

THE FIRST STEP...



Dear Readers,

this issue of the newsletter will mark the 125th anniversary of Hotel Hassler and 40 years of being the manager. Hotel Hassler will always be a significant part of who I am. A place where I grew up, raised my children, and where I still feel the presence of my father and my mother.

I wanted to celebrate this important milestone with the people dearest to me and I decided to organize a party that paid tribute to the Hassler and my personal career path as manager. As I reflect on the journey that I embarked on many years ago and where I am today it leaves me with great pride and accomplishment. This is an important milestone for me that marks the beginning of many more fulfilling years to come.

Time has evolved and brought many positive changes to the story of Hassler such as my children now working alongside me who I know will bring even more prestige to the name Hassler.

As many of you know, my life is not only centered on the Hotel Hassler but also on CABSS. An organization where I reside as President and very passionate about supporting deaf and deafblind children and their families to ensure that they do not feel abandoned and alone. I am very pleased with all of the theoretical, practical and fundraising work being done at the organization.

We have a long-standing collaboration with the Fulbright Commission. Each year, we give an opportunity to a deaf student to specialize in the United States at Gallaudet University. We also collaborate with the George Brown College located in Toronto, Canada which is one of the world's leaders in Deafblindness. In July, we participated at an event dedicated to raising awareness on accessibility and the reduction of communication barriers.

Our annual Christmas event was held for the second year at the Teatro Sistina where spectators got the opportunity to see the musical, "Jesus Christ Superstar", starring the legendary Ted Neely. The event was organized to raise money for deaf and deafblind children. I am very happy to say that it was a great success with more than a thousand people in attendance.

Before saying goodbye, I would like to point out that in this issue of the newsletter there is an important article about CHARGE Syndrome, a rare genetic disorder considered to be one of the major causes of Infantile Deafblindness.

Kindest Regards!



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The Belfast Declaration on Mental Health and Deafness

The ESMHD SIG Meeting & International Conference for Social Provision for Deaf Services was held just weeks before the International Day of Persons with Disabilities. Professionals and renowned international experts met on November 15th to 17th 2018 in the city of Wrexham, North Wales. The aim of the meeting was to encourage the provision of adequate services to deaf people of all ages and training of deaf professionals. Given the theme of the meeting, the Statement on Mental Health and Deafness approved at the 6th ESMHD World Congress in Belfast in September 2014 was strongly recalled and re-launched.

The Belfast Statement is based on the The United Nations Convention on the Rights of Persons with Disabilities which emphasizes equality, freedom and dignity of all individuals as the only way to create an inclusive, supportive and respectful society. A society that individuals with disabilities are guaranteed their fundamental rights and able to fully participate in the political, social, economic, and cultural spheres.

The Belfast Declaration affirms the fundamental rights and freedoms of deaf, hard of hearing and deafblind people of all ages, respecting their linguistic and cultural identity and health needs. The right to full access to treatment and authorization and rehabilitation therapies is emphasized from the assessment phase to the implementation of a treatment plan. The deaf, hard of hearing or deafblind patient must be evaluated and treated by a qualified professionals who are aware of and respectful of their social, linguistic and cultural identity.

In particular, the Declaration affirms the right to mental health services that respects the specific needs of deaf, hard of hearing and deafblind people. The declaration recognizes the right of patients with sensory disabilities and psychological dis-

stress to obtain clear and accessible information in their preferred language, communication method and/or chosen technological device to be able to give a conscious and voluntary consent to treatment.

The Declaration highlights the right to mental health services that puts the person at the center acting, on his/her behalf, in a transparent and responsible way. It recognizes and accepts the role played by family members, friends and other professionals who revolve around the patient. Finally, importance is placed on the individual's right to an equal participation in planning their care program.

In order for these rights to be fully implemented, the Declaration calls for governments, non-governmental organizations, centers offering health services and all interested stakeholders to be actively involved. It is necessary that national laws recognize the rights of deaf, hard of hearing and deafblind people, by promoting the dissemination of culturally and linguistically accessible mental health services starting from an early age.



Stefania Fadda during the "ESMHD SIG Meeting & International Conference Social Provision for Deaf Services"

It is also necessary to develop standardized mental health, early intervention practices and mental health service projects planned and directed by deaf, hard of hearing and deafblind professionals. In addition professionals should be encouraged to share good practices and fight against laws that discriminate against people with sensory disabilities and/or psychological distress that exclude their right to be able to give consent to treatment.

CABSS Onlus, inspired by the Belfast Declaration, is committed daily to offering deaf and deafblind children, and their families, unique early intervention programs in Italy carried out by qualified professionals who have specialized training.

Imagine of Belfast Declaration



CHARGE Syndrome - Part 3: Behaviors

In this issue of our newsletter we would like to focus on how pain, sensory issues, and anxiety impact the behavior of individuals with CHARGE Syndrome.

Pain

Recent research shows that individuals with CHARGE experience more frequent, intense, and chronic pain and may communicate pain in a different way due to communication and sensory deficits. Those who have communication challenges may not have the tools to express pain. Even for those with more formal communication, pain can impact adaptive functioning skills such as understanding, using language and socializing. Recent research has found that individuals with CHARGE tolerate a significant amount of pain and are likely to communicate pain through problem behavior.

Sensory Issues

In CHARGE syndrome all of the sensory systems may be malfunctioning for various reasons. The behaviors in CHARGE syndrome originate from the complex multisensory impairments present in the condition. It can also impact the child's reactivity and access to information in their environment. There may be specific problems with the sensory receptors or problems with the nerve pathways that connect the sensory receptors to the brain such as the cranial nerves and/or malformations of the brain itself. Many children

with CHARGE syndrome have sensory systems that are not integrated enough to effectively respond to stimulation in a well-modulated way. Sensory input can sometimes overload the child and create strong aversive responses creating an increase in self stimulatory behavior.

Anxiety

Anxiety, anxious behavior and diagnosed anxiety disorders are common concerns among individuals with CHARGE syndrome and their caregivers. Individuals with CHARGE syndrome are exposed to situations and circumstances that contribute to a higher level of anxiety such as pain, sensory overload or underload and lack of predictability in the environment. Anticipation of pain can lead to higher levels of anxiety. Sensory impairments and difficulties in gathering and processing information can lead to lack of understanding of one's environment and the progression of events. This lack of predictability can significantly increase anxiety and increase behaviors aimed at communicating distress or obtaining security.

Self Regulation

There are four major systems involved in self-regulation: cognition, behavior, emotion and physiology. Self regulation develops through caregiver responsiveness, the child's interactions with the environment and physiological development. All

three may not be present for children with CHARGE and self-regulation strategies must be taught to help them to be able to regulate pain, sensory systems and anxiety, as well as the ability to identify and express emotions about pain.

In conclusion it is crucial for parents, medical professionals, educators to first rule out pain when problem behaviors occur. Problematic behaviors in CHARGE are complex and need careful analysis before putting interventions in place. Children must be supported in compensating for multi-sensory impairment to ensure that information is accessible. Anxiety can be reduced by marking changes in routine and anticipated events in order to make the environment more predictable. Children need to be taught self regulation skills to be able to work through and be able to communicate when experiencing pain, regulate sensory input and to lower anxiety levels.

Source: Hartshorne, T.S.; Stratton, K.K.; Brown, D.; Madhavan-Brown, S.; Schmittl, M.C. (2017). Behavior in CHARGE syndrome. *American Journal of Medical Genetics*, 175C:431-438. DOI: 10.1002/ajmg.c.31588

The collaboration between CABSS Onlus and George Brown College

The team at CABSS is very dedicated to strengthening their knowledge to providing quality services and programs to deaf and deafblind children 0-6 and their families.

In June 2018 the staff did a refresher course in deafblindness taught by Canadian Deafblind Specialists, Carolyn Monaco and Cheryl Ramey. The team learned new specialized strategies, methodology and techniques that promoted the development of skills and concepts in children who are deafblind.

CABSS has collaborated for years with the prestigious Intervenor for Deafblind Persons Program at George Brown College, located in Toronto, Canada. CABSS has welcomed many students from the program and has hired Laura Harripersad, one of their graduates who has been with CABSS for 9 years now.

The wealth of knowledge acquired from both a theoretical and practical standpoint has kept CABSS informed and aware of how to effectively intervene and support

children who are deafblind and their families, a partnership that we hope will continue to grow and flourish for years to come.



CABSS staff with Canadian Professors Cheryl Ramey and Carolyn Monaco

ACTIVITIES AND PROJECTS

Accessibility and Breaking down Communication Barriers

On July 12th 2018 experts in accessibility and communication and representatives of institutions and associations met to discuss the issues about accessibility and communication at the MoMeC Montecitorio Meeting Center.

The Minister for the Family and Disability, Lorenzo Fontana, provided the opportunity to discuss issues arising from deafness, often know as an invisible disability. Presentations were done about the living conditions of deaf people by a multidisciplinary team of experts and good practices were shared in terms of accessibility and inclusion.

Among the experts, Dr. Stefania Fadda represented CABSS, as Director and President of the European Society for Mental Health and Deafness (ESMHD). She did a presentation on Deafness, Deafblindness and Psychological Well-being.

CABSS and ESMHD believes that depriving deaf and deafblind children the opportunity to communicate in their chosen modality goes against their fundamental rights, as stated in the ESMHD Bad Ischl Declaration (Austria, 2003), in the World Declaration of Worcester (South Africa, 2005), and Belfast Statement on Mental Health and Deafness (Northern Ireland, 2014).

Other presentations were carried out by representatives of ENS, Istituto di Scienze e Tecnologie CNR, Università degli studi di Napoli "L'Orientale", ANIOS - Associazione Interpreti di Lingua dei Segni Italiana, Associazione Gruppo SILIS Onlus, FSSI - Federazione Sport Sordi Italia and del Movimento LIS Subito.



The speakers at the day dedicated to accessibility and breaking down communication barriers

The American Fulbright Scholarship and the many years of collaboration with CABSS

On October 9th, 2018, the Fulbright Orientation for the 2018/2019 was held for American Scholarship winners at the State Institute for the Deaf in the Visual Mediateca conference room. All scholars were warmly welcomed by Paola Sartorio, Executive Director of the Fulbright Commission for Cultural Exchanges between Italy and the United States, and distinguished individuals from the political, academic and scientific world including Roberto Vellano,

Minister Plenipotentiary and Central Director for the promotion of Italian culture and language at the Ministry of Foreign Affairs and International Cooperation; Rodney Ford, Cultural Affairs Officer of the Embassy of the United States of America in Italy; John Ochsendorf, Director of the American Academy in Rome.

The Director of CABSS, Stefania Fadda greeted the scholars and spoke about the active collaboration between CABSS and the Italian Fulbright Commission.

CABSS will welcome a new Fulbright scholar from Boston, Talia Mango who won the Scholarship in Deafness Studies. Talia holds a degree in Severe and Multiple Disabilities with specialization in Deafblindness from Boston College. She will be with us from January 14th to June 14th, 2019 and will carry out a research project with the aim of studying the method of early intervention at CABSS and its impact on the communication of deafblind children. We are very happy to have her join the team!



The participants at the Fulbright Meeting and Orientation



The 70th Anniversary of the Fulbright Program: Presentation by past “Fulbright - Roberto Wirth” Scholar

On December 11th, 2018, The Italian Fulbright Program celebrated their 70th anniversary in Washington D.C. The President of CABSS, Roberto Wirth has collaborated for over 25 years with Fulbright. In 1992 he created a scholarship which he has financed under the Program. Each year, the scholarship has allowed an Italian university student the opportunity to specialize in Infantile Deafness at Gallaudet University, Washington D.C. with the objective of enriching the lives of deaf children once they return to Italy.

The celebration took place in the Auditorium of the Italian diplomatic headquarters in Washington D.C. where former American and Italian Scholars and past students gave an overview of the programs they were involved in thanks to the Fulbright Program.

Lisanna Grosso, the 2017-2018 "Fulbright - Roberto Wirth" scholar shared her positive experience of studying at Gallaudet University and encouraged everyone to return to the U.S. to deepen their knowledge and experience. She expressed her dream of going back to Gallaudet on her own to continue her studies, something now possible thanks to the "Fulbright - Roberto Wirth" scholarship. She hopes that in a couple of years, she'll return to Italy, with more skills and innovative educational materials to utilize with children who are deaf.

such as the Executive Director of the Italian Fulbright Commission, Paola Sartorio, the Italian Ambassador Armando Varricchio and the Assistant Secretary of State for Education and Culture, Marie Therese Royce, who stressed the importance of the program deepening personal ties and strengthening the relationships between the two nations. In fact, more than 14,000 Americans and Italians have participated in the Program since 1948 and thanks to scholarships they had the opportunity to conduct research, teach and study at universities, research centers and non-profit organizations both in Italy and The United States. The Fulbright Program is a symbol of friendship between Italy and the United States and the role that education plays in creating unity between different societies and cultures.



Lisanna Grosso during her speech

The former scholar spoke before a large audience of participants and distinguished guests

The 2019-2020 “Fulbright - Roberto Wirth” Scholarship

We are happy to announce that the 2019-2020 "Fulbright-Roberto Wirth" scholarship is now available. The winner of the scholarship will be able to specialize in Childhood Deafness at Gallaudet University, Washington D.C. (U.S.A.) during the 2019-2020 academic year. All applications must be completed and sent by the 28th of February, 2019.

Candidates must meet the following requirements:

- Is an Italian citizen
- Enrolled in the second year of university or have a degree (triennale or magistrale) obtained at an Italian university
- Good understanding of LIS (Italian Sign Language)
- Good understanding of English

- Practical understanding of ASL (American Sign Language)

Additional information and a new tutorial video in LIS/Italian is now available on the www.fulbright.it and www.cabss.it websites. The tutorial can also be seen directly at the following link: <http://www.fulbright.it/fulbright-roberto-wirth>.

We would like to thank the Italian Fulbright Commission and the American Embassy for creating the video.

Many thanks also to Silvia Palmieri former “Fulbright - Roberto Wirth” Scholar and Sasha Dvorzova the Fulbright Commission’s Program Officer, who explained the step by step process that candidates must take to be successful in applying and going through the selection process on the tutorial video.



Silvia Palmieri and Sasha Dvorzova

FUNDRAISING

The great success of Jesus Christ Superstar: CABSS 2018 Christmas Event

Energy, communication and uniqueness, were some of the adjectives used to describe the musical "Jesus Christ Superstar". A revolutionary production of a story that does not age with time and that has a strong message of spirituality and courage with the ability to reach audiences of all ages.

All of CABSS and ANLAIDS Lazio's guests absolutely loved the show directed by musical writer Massimo Romeo Piparo. A musical that has become a legend to rock music fans, a symbol of rebellion, determination, and the winner of the prestigious Musical World Award.

The event took place on a cold and rainy Sunday evening but not even this could dampen the spirit and enthusiasm of seeing one of the most acclaimed musical productions of all time at the beautiful Teatro Sistina. Once the curtain was raised, a live orchestra was set on a revolving platform on the stage making it a focal part of the musical. The orchestra set the mood and helped the audience connect with the story as they performed original pieces from the Andrew Lloyd Webber and Tim Rice's production. All the musical pieces were directed by Emanuele Friello.

Quotations from the Bible and images were projected on a large screen. The most powerful of such images was the scene in which Pilate whips Jesus thirty nine times. With each blow of the whip, images of the concentration camps of Auschwitz, Martin Luther King, Gandhi, malnourished children flashed across the screen leaving the members of the audience speechless.

The professionalism of Piparo and his team, shone from every angle of the stage as spectators took in the truest form of rock opera. PeepArrow Entertainment knew how to

make the life of Jesus and the universal message of positivity, courage and sacrifice come to life. The musical clearly depicted the lives of Jesus and Judas, illustrating the contradictions of human existence and the complexities of current times.

The productions starred the legendary Ted Neeley who has been loved by several generations of fans. The

production had twenty four acrobats, fire eaters and dancers all choreographed by Roberto Croce and scenographies designed by Giancarlo Muselli.

Before the show some of the supporters of CABSS and ANLAIDS reunited for a Christmas cocktail at the Hotel Hassler before going the theatre at 9 p.m where they were received by Margherita de Bac, a journalist from the Corriere della Sera who writes about health related issues with a focus on rare diseases. Before the production begun she presented the Presidents of CABSS and ANLAIDS Lazio Roberto Wirth and Massimo Ghenzer to the audience and spoke about the organizations.

We sincerely thank Mrs. de Bac and all of our sponsors:

Gold Sponsor: Private Banker Leopoldo Barocci - Sportnetwork - Studio Legale Consolo

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Bronze Sponsor: Blu Insurance Broker - Studio Legale Compagna



CABSS Onlus and ANLAIDS Lazio Onlus guests begin to enter in Teatro Sistina.
Photo by: Noemi Marconi



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

Photo by: Noemi Marconi



The Hotel Hassler Celebrates its 125th Anniversary and Roberto Wirth 40 years as Manager

Piazza di Spagna has an atmosphere that exudes beauty, wonder and grandeur. Home to one of the most famous staircases in the world. At the top of the stairs stands the Church of the Santissima Trinità dei Monti and to its left the Hotel Hassler, the international symbol of Roman hospitality and the "home" of Roberto Wirth.

On November 28th Hotel Hassler celebrated its 125th anniversary and Roberto Wirth his 40th as owner and manager. A hotel that has a history of international awards and has welcomed some of the most famous celebrities, officials and royal families as guests, making it one of the most prestigious hotels in the world and Roberto Wirth, its owner, one of the best known managers in Italy and abroad.

The evening was a tribute to the city of Rome and to the Swiss origins of the Hassler. Roberto Wirth comes from a Swiss dynasty of hoteliers. Its first being Franz-Josef Bucher, considered one of the pioneers of the hotel industry in Europe, who in 1890 commissioned his son-in-law Heinrich Wirth, Roberto's grandfather, to take over the Albergo Minerva and management of the Quirinale Hotel in Rome. Under the direction of Wirth, the hotel soon became one of the most prominent in the city.

In 1921, Oscar, son of Heinrich and father of Roberto Wirth, managed the Hassler Roma with another Swiss hotelier, Alberto Hassler who later became the sole owner. The hotel was then requisitioned during the Second World War by the U.S. Air Force to be used as their headquarters in Rome. In 1947 it was then reopened and entirely renovated.

Roberto Wirth was awarded a medal by the Presidente of the Assemblée Capitolina Marcello di Vito recognizing his work in the hotel industry. The city representatives who attended the celebration included Vice Sindaco Luca Bergamo, the Presidente of the Commissione di Roma Capitale Turismo Carola Penna, the Assessore allo Sviluppo economico, Turismo e Lavoro Carlo Cafarotti and the Ministro del Turismo Gian Marco Centinaio.

The evening was presented by the well-known journalist and friend Corrado Ruggeri who told Roberto Wirth's story. More than 700 guests were present that evening and visually guided on a symbolic journey that encompassed written, visual and concrete historical items that played an important part of making what Hassler is today. Stellar Chef Francesco Aprea delighted guests with delicious food from Switzerland. Waiters and waitresses were dressed in traditional clothing and served typical Swiss dishes such as barley soup, raclette and smoked meats from the Grisons. Guests also had the pleasure of listening to Swiss mountaineers playing traditional alpine horns.

An album with memories of the hotel was a symbolic piece of timeless elegance that was made available to guests to look through. The album included an infinite number of famous celebrities such as: Dwight Eisenhower, Ranieri of Monaco with his

wife Grace Kelly, the Kennedys, Picasso, Gabriel Garcia Marquez, Ingrid Bergman, Audrey Hepburn, Princess Diana, Margaret Thatcher, Francis Ford Coppola and more recently Steve Jobs, Bill Gates, Tom Cruise, George Clooney, Madonna and many others.



Poster about Roberto Wirth's family and philanthropic work



CABSS Onlus full staff.
From left to right: Marta Cidronelli, Director Stefania Fadda, President Roberto Wirth, Giusy Caravello and Laura Harriper-sad

FUNDRAISING

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Donate Online at our website: eng.cabss.it.

PLEASE NOTE

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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 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 indi-

cate 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

eng.cabss.it



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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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