



# IFHOH JOURNAL

*January 2017*

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*The International Federation of Hard of Hearing People (IFHOH) is an international non-governmental organisation representing the interests of more than 300 million hard of people worldwide.*

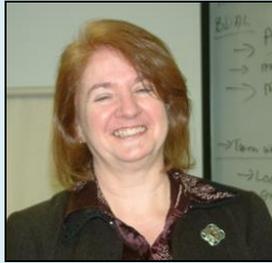
*IFHOH is registered as a charitable organisation at Vereinsregister Amtsgericht, Hamburg, Germany  
- Nr. 69 VR 10 527.*

*IFHOH Journal includes information about IFHOH activities, world news related to hearing loss, articles written by IFHOH members, and much more. It is published four times a year and posted on IFHOH's website, [www.ifhoh.org](http://www.ifhoh.org). The Editor can be reached at [journal@ifhoh.org](mailto:journal@ifhoh.org).*

*All the views expressed in IFHOH Journal are those of the individual writers, and do not necessarily reflect the views of IFHOH.*

# From the Editor's Desk

## From the Editor's Desk



**Carole Willans, Editor**

Dear IFHOH friends,

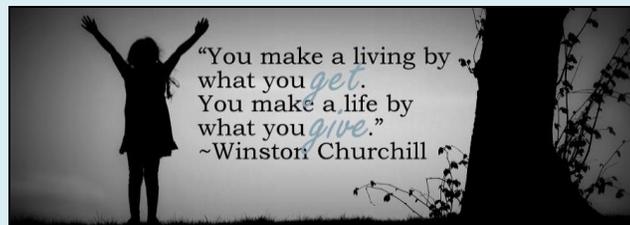
From time to time I am reminded of the huge impact that hearing loss has on my life. Recently I have been going through a period of significant stress, so much so that I have noticed that I seem to be missing more bits and pieces of the wonderful world of sound. It's partly a physical thing as fatigue often has an impact on hearing and partly mental from an occasional difficulty to achieve good focus for listening. If you have hearing loss, you know exactly what I mean.

In trying times, it seems easier to just withdraw into my own cocoon. But I am reminded of Helen Keller, an American author who was the first deaf-blind person to earn a Bachelor of Arts degree: "I am just as deaf as I am blind. The problems of deafness are deeper and more complex, if not more important than those of blindness. Deafness is a much worse misfortune. For it means the loss of the most vital stimulus—the sound of the voice that brings language, sets thoughts astir, and keeps us in the intellectual company of man."



Helen's message has many levels of meaning. For me today, it means that withdrawing from the world of people and of sound should only be for a very short while - a time to recoup strength and focus. It is important to our hearing health and our mental health that we leave the comfort of our cocoon to reconnect quickly with the world so that we keep in touch with the "vital stimulus" of sounds, language, and our relationships with our family, friends and society at large.

Helen Keller overcame obstacles and gave back to the world. All of us are called to do the same in our own modest way - every day. We give the gift of our presence and of our listening to everyone we encounter in our daily lives - and that includes our outreach and work on behalf of hard of hearing people in our respective countries and around the world.



You can send me email at [journal@ifhoh.org](mailto:journal@ifhoh.org) or follow me personally on Twitter @CaroleWillans.

# IFHOH President's Message



Ruth P. Warick, IFHOH President

As 2016 ends and 2017 begins, we enter a period of continued promise of progress. The year's major activity will be the **IFHOH Accessibility Conference on Hearing Loops and Hearing Technology** - plan to attend October 6 to 8, 2017. The venue is The Best Western Plus - Hotel Steglitz International in Berlin (Germany), which is close to transportation, restaurants, and shopping. Our thanks go to Dr. Harold Seidler and Renate Welter of Deutscher Schwerhörigenbund (DSB) and their committee members for their hard work preparing this event. We also wish to express special thanks to Aktion Mensch for its financial support for the conference. Please see page 6 for more information.

You are invited to mark **World Hearing Day** on March 3 using the 2017 theme of *Action for Hearing Loss; Make a Sound Investment*. Any number of activities can be engaged in, from a hearing screening at a school or hospital, a public event to raise awareness, an art contest or a release to the media. Please take photos and report about your event by email to [journal@ifhoh.org](mailto:journal@ifhoh.org). The World Health Organisation (WHO) will share advocacy materials including a theme poster, infographics and banners closer to the date.



IFHOH will be entering into the last phase of its Oticon (Denmark) grant in the coming year. Representations by Dr. Louise Carroll, IFHOH General Secretary, and new IFHOH board member Patrick Gift Egessa from Uganda will occur during a meeting regarding the *UN Convention on the Rights of Persons with Disabilities* to be held in Geneva in March and again in August. Representations will also be made when the Conference of State Parties meets in New York City in June, 2017. I will be involved in these meetings, supported by Louise and Patrick. We are also continuing to emphasize the importance of the UN Sustainable Development Goals for achieving progress for our community. By the way, if you have not already done so, please view and use the CRPD video available on our website.

IFHOH is part of the International Disability Alliance and we are pleased to learn that this organisation has received a grant from the Department for International Development of the UK (DFID). A meeting of the program committee will be held in March in Geneva. There is potential for capacity-building within the project for IFHOH. The grant will be for a three-year period.

Avi Blau, IFHOH Vice-President, will be representing IFHOH at a joint meeting of WHO and the International Telecommunications Union (ITU) in March in Geneva. The consultation is aimed at **reducing the risk of hearing loss posed by unsafe listening behaviour**. Specific objectives are to: create a global partnership to promote safe listening; develop and promote, in partnership with other stakeholders, standards for safe listening devices; initiate actions to promote safe listening through the use of technology, and develop standards for safe listening devices/software.

Please also plan to attend the **IFHOH BGM** along with the **EFHOH AGM** to be held April 13-15, 2018 in lovely Ljubljana, Slovenia. Our thanks to the Union of the Associations for the Deaf and Hard of Hearing of Slovenia for their successful bid to host this event. Ljubljana is Slovenia's capital and largest city. It is known for its university population and green spaces. The curving Ljubljanica River, lined in outdoor cafes, divides the city's old town from its commercial hub. Ljubljana has many museums, including the National Museum of Slovenia.



I wish you continued hearing health care and happiness and a world of peace and prosperity.

With best regards,  
Ruth

Dr. Ruth Warick, President of IFHOH  
[president@ifhoh.org](mailto:president@ifhoh.org)

*Editor's Note: The Hearing Loss Association of America (HLAA) recently published an interview of Dr. Ruth Warick by Barbara Liss Chertok in Hearing Loss Magazine - **Raising Awareness of Hearing Loss on a Global Scale** - [Read the whole article here.](#)*

# IFHOH Accessibility Conference on Hearing Loops and Hearing Technology

The **IFHOH Accessibility Conference on Hearing Loops and Hearing Technology** will be held in Berlin, Germany from October 6 to 8, 2017. The venue is The Best Western Plus - Hotel Steglitz International. An IFHOH member organisation, Deutscher Schwerhörigenbund (DSB), is planning for what will be the 4<sup>th</sup> in a series of international conferences devoted to hearing loops and technology, the most recent one having taken place in Eastbourne, England, four years previous.



The overall conference theme is **Future Loops** - with a focus on the latest loop technology and the many forthcoming alternatives providing access in public places. Please click on the following links to find out more on:

- [The Topics of the Conference](#)
- [The Target Group of the Conference](#)
- [The Conference Center and the Hotel](#)
- [Sponsorship and Exhibition Opportunities for Businesses and Professionals](#)
- [The Conference Programme](#)

The conference registration form and a link to the accommodation booking are currently expected to become available in mid-January at: <http://www.schwerhoerigen-netz.de/IFHOH-2017/english>

IFHOH and DSB thank Aktion Mensch most sincerely for its generous support of the conference. Find out more about the charity [Aktion Mensch here](#) (available in German only).



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For more information about the conference, please contact:  
Gudrun Brendel, Conference Manager, [IFHOH-2017@schwerhoerigen-netz.de](mailto:IFHOH-2017@schwerhoerigen-netz.de)

You may also contact the Deutscher Schwerhörigenbund (DSB):  
Renate Welter, Vice President, [dsb@schwerhoerigen-netz.de](mailto:dsb@schwerhoerigen-netz.de)

# IFHOH Human Rights Advocate Wins Achievement Award



**Louise Carroll**  
IFHOH General Secretary

IFHOH is pleased to congratulate its *General Secretary* Dr. Sinden-Carroll for being named a recipient of the prestigious Henry Viscardi International Achievement Award. Dr. Ruth Warick, President of IFHOH, stated that Louise's work on the *UN Convention on the Rights of Persons with Disabilities (CRPD)* has been enormously important for advancing hard of hearing issues and that it is heartening to see a leader in the community get recognition.

Dr. Louise Sinden-Carroll, who has a moderate hearing loss, is employed as the Chief Executive of New Zealand's National Foundation of the Deaf. Besides being *General Secretary*, she is also IFHOH Human Rights Officer. She is the lead author of IFHOH's CRPD Toolkit and the CRPD Video. She facilitated Human Rights CRPD workshops and a discussion group for people with hearing loss from organisations in 26 countries.\*

Dr. Sinden-Carroll believes the *UN Convention on the Rights of Persons with Disabilities (CRPD)* is a global tool that provides people with disabilities with the strength and capabilities to achieve a quality of life equal to that of people without disabilities. "One hundred and sixty UN State parties have signed the CRPD," she says. "Governments cannot continue to deny the provision of reasonable accommodations needed to achieve equality for people with disabilities in all aspects of their lives including employment, in health, social and cultural too."

In 1999 when she became hard of hearing through an injury, Dr Sinden-Carroll learned first-hand just how much of a challenge such a disability is. The challenge is further and significantly compounded by the lack of understanding in mainstream society. "In fact, in some quarters at that time, it was not even recognised as a disability," she says. She

believes this has changed quite dramatically during the past eight years with the UN Committee on the CRPD now querying States when reporting on whether captioning and other such options are being provided to people with hearing loss.

In September 2016 Dr. Sinden-Carroll graduated with a PhD following the submission of a public policy thesis considering the New Zealand Government's response to prisoners with hearing loss.

The US-based Henry Viscardi International Achievement Award recognizes



Dr. Henry Viscardi Jr. surrounded by friends

exemplary leaders within the disability sector globally for their extraordinary contributions to all of society. Viscardi Center founder Dr Henry Viscardi Jr. was one of the world's leading advocates for people with disabilities and served as a disability advisor to eight U.S. Presidents from Franklin D. Roosevelt to Jimmy Carter. In 2016 only eight people were recognized worldwide.

IFHOH has released a video on the Convention on the Rights of Persons with Disabilities (CRPD) and how it applies to uphold the rights of people with hearing loss. The IFHOH CRPD video is available at: [www.youtube.com/watch?v=G35rLmCobrY](http://www.youtube.com/watch?v=G35rLmCobrY) and we encourage you to use it when educating your members about the CRPD. The popular IFHOH CRPD Toolkit are available at: [www.ifhoh.org](http://www.ifhoh.org).





WHO Collaborating Centre for  
Prevention of Deafness and  
Hearing Loss



International Federation of Hard Of Hearing  
People



China Rehabilitation Research Center for  
Deaf Children

# Multi-country Workshop on Ear and Hearing Care in WHO Western Pacific Region



By Avi Blau, IFHOH Vice President

The World Health Organization (WHO) arranged a workshop on Ear and Hearing Care (EHC) in Beijing, China, on December 6-7, 2017. The local host organization was the CRRCDC which is a rehabilitation center for deaf children.

Among the participants there were representatives from China, Mongolia, Brunei, Singapore, Malaysia, Japan, South Korea, Australia, Laos, Cambodia and Vietnam. Each one provided information on the state of hearing care and hearing loss in their countries.

In the discussions, good arguments were sought on why the prevention of hearing loss and rehabilitation of hearing loss are so important. The cost of hearing loss to society was mentioned as important reason, but one that is hard to explain to decision makers.

Many of the participants were otolaryngologists and ENT doctors, so the main approach was the medical model that looks at a persons with hearing loss as patients. But there was openness to hear the side of the HOH persons themselves. Dr. Billy Martin from Singapore gave a good presentation. He estimated the cost of hearing loss to the society in his country to be close to 1 billion USD a year!



# EFHOH News

EFHOH's last Board meeting was in October and was held at the Light House in Helsinki, Finland. We discussed different topics, including our program for 2017. We were pleased that the new IFHOHYP President Victor Rehn was able to participate.

IFHOH Vice President Avi Blau, EFHOH Secretary Aïda Regel Poulesen and EFHOH President Marcel Bobeldijk were in Copenhagen, Denmark in October. They met with Majbritt Garbul Tobberup, President of the member organisation in Denmark, Horeforeningen. She provided an interesting overview about her organisation and the situation for hard of hearing people in Denmark. The meeting was held in the most accessible building in Europe, the Disability House (see photo on right).



Then Avi, Aïda and Marcel participated in the Hear-It AGM, representing the interests of hard of hearing people worldwide. For more information about this organisation, visit its website at [www.hear-it.org](http://www.hear-it.org).

As a Board member of the European Disability Forum (EDF), Marcel participated in board meetings in Slovakia. One of the most important results of these meetings was the new EDF resolution on the *European Accessibility Act*. [Read more](#).

The European Day of Persons with Disabilities conference took place in Brussels, Belgium on November 29-30. The theme was the 10<sup>th</sup> anniversary of the CRPD.



The EFHOH AGM and Conference 2017 will be taking place in London (United Kingdom). See the following pages for more information.



## **EFHOH / NADP AGM and Conference**

**May 5 – 7, 2017**

***‘Staying connected, informed and empowered’***

**Friend’s House, 173-177 Euston Road, London, NW1 2BJ  
London, United Kingdom**

The European Federation of Hard of Hearing People (EFHOH) will hold its AGM and Conference in London, UK with the theme '**Staying connected, informed and empowered**'. This event will be hosted by the National Association of Deafened People (NADP). This is a unique opportunity to meet delegates from hard of hearing community across Europe.

The event provides an opportunity to hear directly from the most senior leaders in hearing care and disability movement, discover innovative work led by industry, and network with colleagues from across the sector.

The venue is fully accessible with hearing loops and for persons with mobility issues.

For information on the conference site: <http://www.friendshouse.co.uk/getting-here>

### **Speakers** (confirmed to date)

- Dr. Laszlo Lovasz (Expert at the UN CRPD Committee and EU Parliament Advisor)
- Lilian Greenwood (MP for Nottingham South and NADP President)

- Søren Hougaard (Secretary General of the European Hearing Instrument Manufacturers Association)
- Mark Laureyns (President of the European Association of Hearing Care Professionals)
- Gareth Ford-Williams (Head of Accessibility, BBC Design and Engineering), and
- Chris Wood (Action on Hearing Loss)

Why should you attend? Here is why!!



**Program Excerpt**

**Friday, May 5 - afternoon**

*Annual General Meeting of EFHOH*

**Saturday, May 6**

*Conference - Speakers and topics affecting the UK and the international community*

*Lunchtime - NADP AGM*

*Gala Dinner - Ticket-only dinner at an iconic London venue*

**Sunday, May 7 - social program**

Contact event organisers at [events@nadp.org.uk](mailto:events@nadp.org.uk)

**HOW TO CONTACT EFHOH**

Remember... you can follow EFHOH via Facebook and Twitter. The addresses are:

EFHOH	@efhoh
Marcel Bobeldijk	@marbob32
Lidia Best	@best_lidia

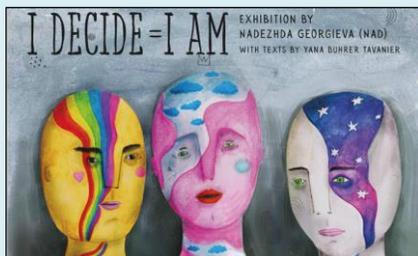


# Celebrating the International Day of Persons with Disabilities

Every year, December 3 marks the International Day of Persons with Disabilities (IDPD), which has been promoted by the United Nations since 1992. This year's theme was *Achieving 17 Goals for the Future We Want*. The theme refers to the 17 Sustainable Development Goals (SDGs) of the *2030 Agenda for Sustainable Development* adopted by world leaders in September, 2015. In its press release of December 3, 2016, IFHOH stated that its constituency represents one of the largest groups of persons with disabilities (one-third of all persons with disabilities in the world) and that it is important that no one should be left behind. "On this International Day of Persons with Disabilities, all hard of hearing people should be remembered and included." [READ THE PRESS RELEASE](#).

The World Health Organisation (WHO) also celebrated "a day for all", highlighting that disability is part of the human condition and a manifestation of diversity in our societies. WHO supports efforts around the world to remove barriers to health facilities, to strengthen and extend rehabilitation; and support the development of Community-Based Rehabilitation (CBR).

This year WHO has furthered a number of initiatives, including co-hosting of the 2nd CBR World Congress in Malaysia in September, making progress towards finalization of the *Guidelines on Health-related Rehabilitation*, and building capacities in countries to implement the Model Disability Survey.

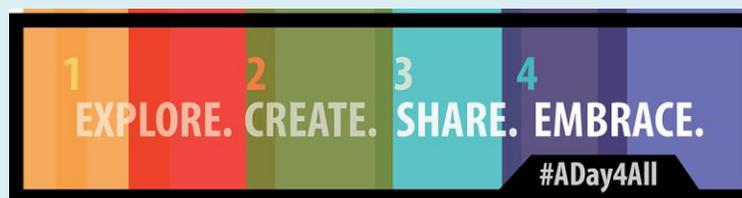


To celebrate International Day of Persons with Disabilities 2016, WHO headquarters held an art exhibition at the Palais Wilson in Geneva. The exhibition "I decide = I am" showcases the work of two Bulgarian artists, and explores issues relevant to people with mental health concerns and intellectual disabilities.

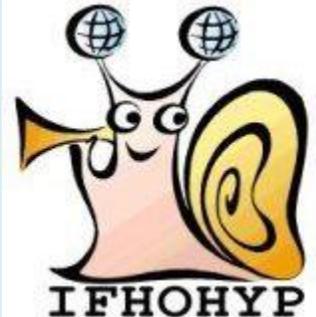
Social media platforms were also created, to promote the rights of people with disabilities. These include a web site [www.aday4all.net](http://www.aday4all.net), as well as *A Day for All* social media presence on Facebook and Twitter.

#### Related links:

- International Day of Persons with Disabilities <http://www.un.org/en/events/disabilitiesday/>
- *World Report on Disability* [http://www.who.int/disabilities/world\\_report/2011/en/](http://www.who.int/disabilities/world_report/2011/en/)
- *WHO Global Disability Action Plan 2014-2021* <http://www.who.int/disabilities/actionplan/en/>
- Model Disability Survey <http://www.who.int/disabilities/data/mds/en/>
- *A Day for All* website <http://www.aday4all.net>



# IFHOHYP 2017 STUDY SESSION



The International Federation of Hard of Hearing Young People (IFHOHYP) is preparing for the IFHOHYP 2017 Study Session with the theme of *Building a Socially Inclusive World through Personal Empowerment*. This event is taking place at the European Youth Centre in Budapest, March 6 to 11, 2017. Open to young people from 18 to 30 years old, it is being organised by IFHOHYP in cooperation with the Council of Europe (Youth Department).

The aim of the study session is to improve the effectiveness of the participants' respective organisations in defending and promoting human rights and social inclusion, as well as to develop the competence of the young hard of hearing people themselves. More complete information on the IFHOHYP 2017 Study Session is available at [drive.google.com/file/view/](https://drive.google.com/file/view/).



Photo above:

Four “generations” of IFHOHYP Secretaries met in Burnaby, British Columbia, Canada in August 2016  
(From left to right) Sidsel Munkebo Hansen, Ece Saygi, Bowster Kai, and Astrid Fejrø



# Turning Hearing Loss into Sound

## Premiere of the Opera TMIE in Lisbon, Portugal

By Siegfried Karg



*Why did the contemporary Portuguese composer Carlos Alberto Augusto name his opera about hearing loss TMIE? TMIE stands for a gene defect which can be the cause of hereditary hearing loss.*

*With his musical masterpiece **TMIE: Standing on the Threshold of the Outside World**, the composer presents the topic of hearing loss in terms of music. The main characters are based on two women with hearing loss who have attained outstanding achievements in their fields: the American astronomer Henrietta Swan Leavitt and the Canadian computer scientist Beverly Biderman.*

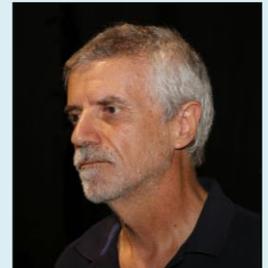
One problem a person with hearing loss faces is the search for the cause of their personal hearing disability, especially when there are no discernable contributors such as noise exposure in the workplace or illness. A possible genetic factor has now been

determined, even if this does not mean that the hearing loss could have been prevented. A gene with the difficult name TMIE (Transmembrane Inner Ear) is responsible for the healthy development of hair cells in the ear. If this gene is defective, then hearing loss is almost inevitable.

For Beverly Biderman, who has had a profound hearing loss since childhood, this gene defect is probably responsible for her progressive hearing disability. She, along with other members of her family, took part in a study by the US National Institute of Health (NIH) in 2002 in which their DNA was tested for the presence or absence of this gene.

It is to the credit of the Portuguese composer and author Carlos Alberto Augusto, who studied under R. Murray Schafer of Simon Fraser University in Canada, that he took on this subject matter in his opera entitled "TMIE", thus bringing awareness of the issue to a broader public.

With his solo opera in four parts for soprano and electronic music, Augusto creates a connection between ancient mythology and the present day. In musical form he tells the story, in English, of two women who, despite being hearing impaired, have made lasting contributions in their fields.



Carlos Alberto Augusto

The first is the American astronomer Henrietta Swan Leavitt (1868-1921) whose observations of the stars in the Harvard College Observatory laid the groundwork for the discoveries of the renowned astronomer Edwin Hubble (1889-1953), after whom the Hubble telescope is named. Leavitt developed a new photographic measuring technique that found recognition in 1913. When her name was put forward for a Nobel Prize in 1925, the recognition came too late, as she had already passed away in 1921.

In the opera, Henrietta Leavitt is characterized in the role of the ancient goddess Selena. The text of the opera dealing with Leavitt is based on the book *Miss Leavitt's Stars: The Untold Story of the Woman who Discovered How to Measure the Universe* (2005), by George Johnson. Thanks to

Johnson's book, her story became known beyond the small circle of astronomers. Asteroid 5383 was named after Leavitt in 1973 in her honor.

The second woman portrayed in the opera is Beverly Biderman, born in 1946, a retired systems analyst. Biderman chose to be fitted with a cochlear implant at the age of 46 after having been deaf for most of her life. She described her experience of learning how to hear again in the book *Wired for Sound. A Journey into Hearing*, which was first published in 1998 and is now available in a newly expanded and revised edition. Biderman's book served the composer Augusto as the basis for the libretto for the mythological character Mesedjer. Through this character he describes the experience of receiving a cochlear implant, the implantation of the electrodes into the cochlea, the activation of the speech processor after healing, the process of learning to make sense of sounds again.



Beverly Biderman, Carlos Alberto Augusto and Marina Pacheco

Quite fittingly, Augusto chose to have electronically produced music accompany the singer rather than an orchestra. Ten loudspeakers distributed strategically around the room are controlled individually to create the desired effect of completely enveloping the audience with the music.

The opera debuted in the Cultural Center for Electronic Music in Lisbon, Portugal, on September 8, 2016, as a co-production with Miso Music Portugal under artistic director Miguel Azguime. The award-winning young soprano Marina Pacheco brought the characters to life. Her singing was supported visually by video installations, helping display which role she was interpreting. In addition, her use of different English accents made it easier for the audience to distinguish the different roles. Pacheco's moving rendition of the partially spoken, partially sung hour-long opera resulted in a masterful performance.



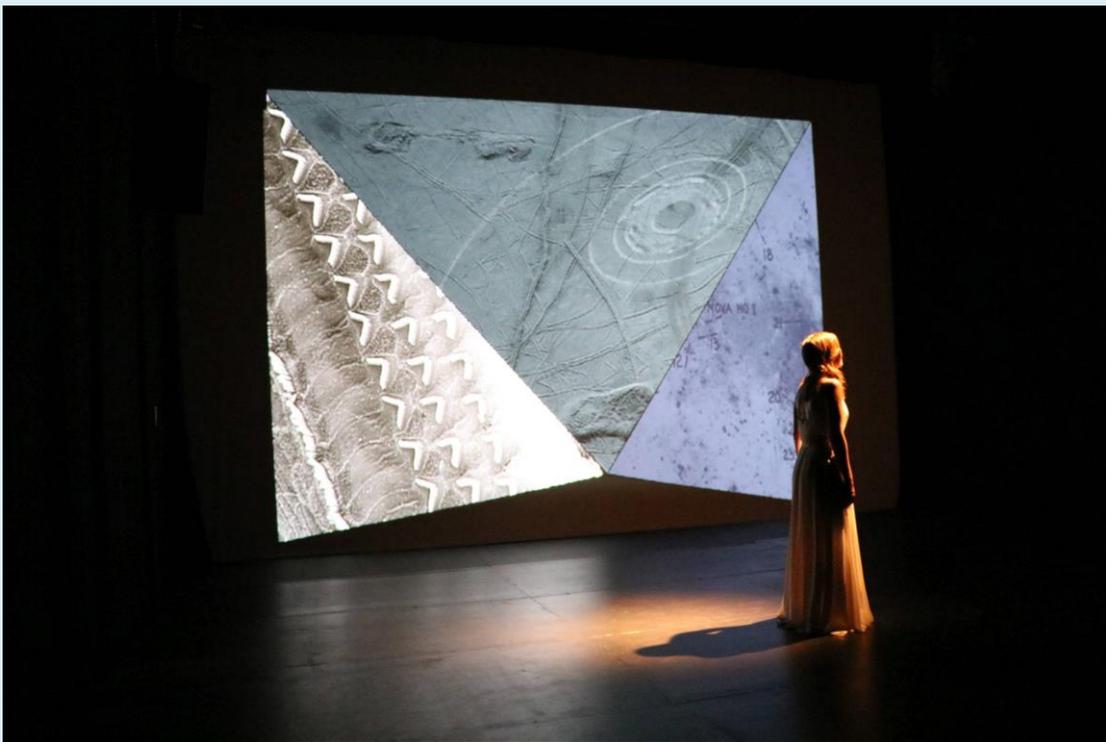
The fact that one of the women on whom the opera is based was present in the audience added to the success of the opening. Beverly Biderman had travelled from Canada to Portugal especially to be able to attend the premiere. Some of the well-deserved generous applause at the end of the performance was meant not only for the composer Carlos Alberto Augusto and the soloist Marina Pacheco, but also for Beverly Biderman, on whom the character Mesedjer is based.



Beverly Biderman

The solo opera TMIE could help to inform a broad audience of all those dealing with hearing related issues about the experience of cochlear implants. Since the text of the opera is in English it is accessible to many people all over the world. International gatherings of ENT-doctors, audiologists, and hearing-healthcare providers would be eminently suitable venues for live performances of this opera.

Beverly Biderman expresses her gratitude for the deeply moving experience of attending the world premiere of the opera "TMIE" in the following words: *In Lisbon for the premiere of the opera TMIE: Standing on the Threshold of the Outside World (from the spirals of the universe to the spirals of the inner self), based on my book, Wired for Sound: A Journey into Hearing. The opera was magnificent. My character (Mesedjer) was paired with the character of Henrietta Leavitt, the deaf 19th century Harvard astronomer (Selena). The digitized music by Carlos Alberto Augusto was magnificent: often mesmerizing, sometimes terrifying, always gripping. Solo soprano Marina Pacheco sang three (!) parts -- as Mesedjer, as Selena, and as Coryphaeus (representing the chorus commenting from the side). Pacheco acted out the three parts with passion and finesse, changing her personality, her singing voice, even her posture as she sang each role. Lighting and dramatic backdrops also helped to tell the story and bring its parts together. A truly bravo performance! The first time an opera has ever dealt with deafness as its subject. I was tremendously moved to be there and to hear my words sung with such emotion and artistry. I see a great future in store for TMIE.*



# Uganda National Association of the Hard of Hearing - UNAHOH



By Patrick Gift Egessa



Uganda National Association of the Hard of Hearing (UNAHOH) is a registered non-governmental, non-profit making, and non-political organisation whose vision is to unveil the potentials of hard of hearing people in Uganda - people with hearing impairment, like *the late deafened people, the hard of hearing children, and the hard of hearing youth/students.*



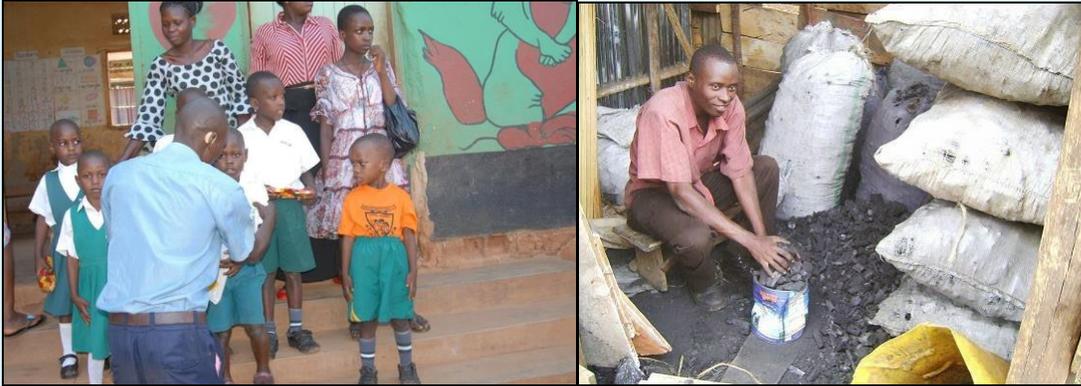
CRPD Started in Uganda in 2014



CRPD in Uganda 2016 – Photo (l. to r.) Patrick, Kasirivu, Mzee, Sarah, Dora, Sylvia and participants in February, 2016

The UNAHOH is preparing for upcoming workshops on the CRPD to take place on September 15 and 16, and on November 22 and 23, 2017.

A hard of hearing school opened in Uganda. Children love learning and studying. Support is needed to help them get education. Hard of hearing children need support for school fees, reading books, writing materials, clothes, mattresses and many other items. John, pictured below, is a teacher, and also works with charcoal. Persons who are hard of hearing with professions can also do business for self-reliance. As an objective, UNAHOH supports hard of hearing persons by training them to be financially stable.

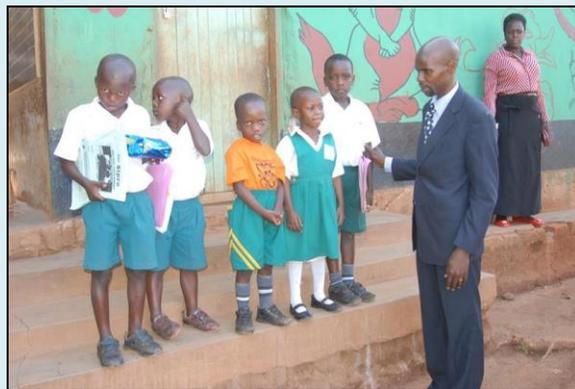


John, who is hard of hearing, teaches Primary 2 &3 - He is self-cooking charcoal as well as teaching

## EDUCATION OF HOH IN UGANDA

*UNAHOH's key objectives and proposed year plan agenda for 2017 are:*

- Lack of HOH schools in Uganda
- Lack of hearing aids
- Difficulties in communication



Patrick Gift Egessa poses for a photo with children at Kitebi Star Primary School

# Journey to University

## For Deaf and Hard of Hearing Students

By Duong Phuong Hanh



These days we often hear the message "an inclusive society for all", which expresses much benevolence, especially for people with disabilities. Disability rights laws enacted by the Vietnamese Congress in 2010 and the signing of the UN CRPD in 2014 indicate that the Party and the Vietnamese Government have seriously considered and support people with disabilities in general, and the Deaf and hard of hearing in particular. However, in terms of achieving progress in social inclusion, there is no denying that people with disabilities face a lot of obstacles.

According to the Central Population and Housing Census Steering Committee, in 2009 Vietnam had around 2.5 million Deaf, Hard of Hearing and Late-Deafened persons. The process of inclusive education for hard of hearing people, from kindergarten to university, is the same as for people without hearing disabilities. Special schools for the Deaf end at to secondary level and there are no high schools for deaf students to continue their education. It is true that university is not the only way; however, if qualified deaf students have no place to learn, there will be great inequity in opportunities for them.

In the last three years, the Center for Research and Education of the Deaf and Hard of Hearing (CED) has successfully supported one deaf student in his secondary education at the special school and integrated education at the Centre for Continuing Education. This year, he was accepted into Nguyen Tat Thanh University. This successful case is very promising, though it doesn't commonly speak for the whole progress of the transition from secondary special education to inclusive high school education. In addition to that, to help all deaf students on their journey to university, we need more supporting sources rather than CED alone.



As a result, a seminar: *Journey to University for Deaf and Hard of Hearing Students* was organized by CED for 130 guests on October 30, 2016 at the General Science Library of Ho Chi Minh City, for the purpose of sharing information, experiences and calling for the cooperation of related parties to support deaf students with their opportunities in universities. The workshop was accessible with captioning in Vietnamese and sign language interpretation. (Photo: the author speaking at the event)

The seminar received the attention and participation of honored delegates as:

- Dr. Huynh Cong Minh - Former Director of Education and Training Department in HCM City;
- Ms. Nguyen Tu Du - Deputy Manager of Kindergartens, Deputy Director, Standing Committee, Steering Committee on Education for Children with Disabilities and Disadvantaged Children, Education and Training Department in HCM City;
- Mr. Le Chu Giang - Representing the Department of Labour, War Invalids and Social Affairs;
- Mr. Vinh Quoc Bao - Deputy Director of General Science Library of Ho Chi Minh City;
- Mr. Lam Ke Chi - Principal of Centre for Continuing Education in District 1;
- Tran Thi Ngoi - Principal of Hy Vong school in District 1;
- Nguyen Thi Xuan Mai - Principal of Hy Vong school in District 6;
- Mr. Tran Van Le - Director of the Supportive Center for Development of Inclusive Education in Tien Giang;
- Representatives of schools and centers, companies, the Orthopaedics and Rehabilitation Hospital, non-governmental organizations, parents, teachers, social work club, students, representatives of the HCM Deaf club, Tien Giang Deaf club, and others; and
- The Press, radio broadcast and television stations: HTV, VTV in HCM City, Voice of Vietnam, Vietnam News Agency in HCM City, Tuoi Tre Newspaper, Dan Tri Newspapers, law-focused newspapers, and more.

**The seminar arrived at conclusions on the following key issues:**

**The first is the student themselves:** the success of students with hearing loss in their inclusive education, first of all, depends on themselves. They must have strong will, continuous inquisition in studying, the habit of questioning when not understanding something, and bravely asking for help when needed. Deaf and hard of hearing people are themselves the most important factor of their success. In addition, people with hearing loss should also have skills such as lip reading, independent-living skills and more ... that way it is easier to achieve integration.



**The second is the role of the family:** Parents should detect their children's hearing loss early and equip them with hearing aids from a young age. Family also has to accept the situation no matter what, and puts effort into raising deaf children. Throughout the development of children, the proper attention and support are a must, which means parents should accompany their children in learning, doing, playing and most importantly, always be there to provide support. It is important to encourage children to be independent rather than to help them in everything. Moreover, parents have to search for information and knowledge to teach children, and seek support from the community. When children are taking part in inclusive education, their family should support and care for them so that the children can keep up with the programs at school.

**Thirdly, the role of schools and teachers:** Representatives of high schools emphasized the greater difficulties of the programs compared to elementary school and encouraged deaf and hard of hearing students who pursue inclusive education to study with double efforts, compared to the students with normal hearing, to obtain real knowledge. Besides, teachers of inclusive schools and supportive centers for development of inclusive education should work together to come up with proper educational plans for children with hearing loss.

**Fourthly, the role of the society and community:** Society should recognize the efforts of deaf students and help them develop their potential.

**Fifthly, the role of government:** Although the Government has a policy of exemption from the high-school graduate examination for deaf and hard of hearing students with fair grades, we still need supporting policies to establish a special high school for deaf students.



The collaboration in education among the three environments: family, school and society is extremely necessary to help students with disabilities access inclusive education in general, and students with hearing loss pursue high education in particular.

The spirit of the seminar can be summarized as follows: Ho Chi Minh City has the largest number of special schools for the Deaf, supportive centers for development of inclusive education, and students with disabilities who participate in inclusive education in Viet Nam. In accordance with such favorable conditions, deaf and hard of hearing students must spend great effort to gain access to University.

*Editor's Note: Duong Phuong Hanh is the Director of the Center for Research and Education of the Deaf and Hard of Hearing (CED), as well as President of the Asia Pacific Federation of the Hard of Hearing and Deafened (APFHD). She is a former IFHOH General Secretary.*



# Calendar of Events

## Calendar of Events

### May 5-7, 2017 - EFHOH / NADP AGM and Conference



Location: London, United Kingdom

Information: <http://www.efhoh.org/news>

Contact: [events@nadp.org.uk](mailto:events@nadp.org.uk)

The theme is *Staying Connected, Informed and Empowered.*

See page 11 of this issue for more information.

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### May 25-27, 2017 - Canadian Hard of Hearing Association Conference

Location: Sidney, B.C. (near Victoria), Canada

Information: <http://www.chha.ca/conference/>

Contact: [conference@chha.ca](mailto:conference@chha.ca)



Mary Winspear Centre – Conference Venue

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### June 18-22, 2017 - 12<sup>th</sup> IC BEN Congress on Noise as a Public Health Problem

Location: Zurich, Switzerland

Information: [www.icben2017.org](http://www.icben2017.org)



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## October 6-8, 2017 - 4<sup>th</sup> IFHOH Accessibility Conference on Hearing Loops and Hearing Technology

Location: **Berlin, Germany**

Information:

Website: <http://www.schwerhoerigen-netz.de/IFHOH-2017/english>

FaceBook: [FB/EuropeanFederationOfHardOfHearingPeople/4th Hearing Loops](https://www.facebook.com/EuropeanFederationOfHardOfHearingPeople/4thHearingLoops)

Contact: Gudrun Brendel, Conference Manager, [IFHOH-2017@schwerhoerigen-netz.de](mailto:IFHOH-2017@schwerhoerigen-netz.de)



This important conference is organised by the German association DSB in collaboration with IFHOH. See page 6 of this issue for more details and useful links.

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## October 11-15, 2017 - ALDAcon 2017

Location: **Orlando, Florida, U.S.A.**

Information: [www.alda.org](http://www.alda.org)

Call for Proposals: <http://www.alda.org/aldacon2017/CFP-Final-12-28-16.pdf>



# News Bytes

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### EUROPEAN DAY OF PERSONS WITH DISABILITIES



Since 1992, the International Day of Persons with Disabilities (IDPD) has been celebrated annually on December 3 around the world. At the European level, this time is marked annually through the European Day of Persons with Disabilities, including a two-day conference organised by the European Commission and the European Disability Forum (EDF) on November 29-30, 2016 in Brussels with the theme:

['Marking 10 years since the adoption of the UN Convention on the Rights of Persons with disabilities'](#).

### EUROPEAN HUMAN RIGHTS REPORT 2016



The first *Human Rights Report* of the European Disability Forum (EDF) was published in November, 2016. This issue is the first in a series of reports on the human rights of persons with disabilities in Europe. It provides an overview of the state of the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) in Europe. The EDF is an independent organisation representing the rights of 80 million persons with disabilities in Europe. The report is available on the EDF website at [www.edf-feph.org](http://www.edf-feph.org), including accessible PDF and Easy-to-Read versions.

### HEARING THE VOICES OF WOMEN WITH DISABILITIES

Every year, November 25 marks the International Day for the Elimination of Violence against Women. The CRPD recognizes under article 6 that "women and girls with disabilities are subject to multiple

discrimination" and that states should take measures "to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms". The EDF has established a Women's Committee, of which Lidia Best is a member. Lidia is already well known to IFHOH as she is the Vice President of the European Federation of Hard of Hearing People (EFHOH). As part of efforts to mark the International Day by giving a voice to women with disabilities, Lidia shared some of her insights during a joint interview on some of the difficulties faced by women and girls with disabilities in today's Europe and on how governments can protect their rights. [READ INTERVIEW](#).



## TREATMENT SHOWN TO REDUCE CHEMOTHERAPY-INDUCED HEARING LOSS IN CHILDREN AND YOUTH



David R. Freyer, DO, MS, director of the Survivorship and Supportive Care Program in the Children's Center for Cancer and Blood Diseases at the Children's Hospital Los Angeles, was lead author and chair of a study published December 2, 2016 on a treatment to remove chemotherapy-induced hearing loss in young people. Investigators from the Children's Hospital of Los Angeles and from 37 other Children's Oncology Group hospitals in the U.S. and Canada have determined that sodium thiosulfate prevents cisplatin-induced hearing loss in children and adolescents with cancer. Results of this randomized, controlled, phase 3 study, called ACCL0431, have been published in the early online edition of *Lancet Oncology*. [READ MORE](#)

## ON Semiconductor Gains CES Recognition for Ingenuity in Both Internet of Things & Wireless Medical Technology

Ezairo® 7150 SL, an open-programmable DSP-based hybrid made by ON Semiconductor, enables wireless connectivity in hearing aids and cochlear implants using DSP-based System-on-Chip and Smart Passive Sensors. ON Semiconductor was recently named CES 2017 Innovation Awards honoree in two different categories by the U.S. Consumer Technology Association (CTA)™. [READ MORE](#)



## TEXT 9-1-1 FOR EMERGENCY SERVICES IN CANADA

The [Canadian Wireless Telecommunications Association](#) (CWTA) and its wireless carrier members, in partnership with public safety agencies across the country and the [Canadian Radio-television and Telecommunications Commission](#) (CRTC), observed the [International Day of Persons with Disabilities](#) on December 3 with the marking of the national availability of [Text with 9-1-1](#) (T9-1-1) service for Canada's Deaf, Deafened, Hard of Hearing and Speech Impaired (DHHSI) community.



## DIABETES AND HEARING LOSS

A large cohort study of young and middle-aged men and women, published in the *International Journal of Epidemiology* on November 6, 2016, has found that diabetes can be associated with the development of bilateral hearing loss. More specifically, persons with diabetes have a moderately increased risk of future hearing loss. [READ MORE](#)



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## Help us thank our sponsors by supporting them!

*IFHOH is grateful for the generous and continuous support provided by our corporate sponsors. In the previous issue, we introduced you to **Amplifon** – today we introduce you to three other key IFHOH sponsors: **Bernaфон, Widex and ReSound!***

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**Your hearing • Our passion**

*Since 1946, **Bernaфон** has been passionate about developing quality hearing systems that enable people with hearing difficulties to enjoy authentic listening experiences. With Swiss Engineering, precision technology, and our commitment to individual service, we strive to exceed our customers' expectations. Our aim is to provide extra value to our partners every day. Bernaфон representatives and employees in over 70 countries fulfill our vision to help people with impaired hearing communicate again without limitations.*

**WIDEX**®  
HIGH DEFINITION HEARING

*At **Widex**, we combine years of understanding with a natural curiosity in finding solutions to individual hearing loss. Our uncompromising approach to innovation has led to such advances as the world's first fully digital in-the-ear hearing aid, as well as our own revolutionary wireless technology. But hearing aids are more than the technology inside them. Not only should they help people hear better, they should be comfortable and easy to wear. We concentrate just as much on design of hearing aids as on technology to create a near-natural hearing experience. We also believe in clever solutions and that things can always be done better. Our entirely CO2-neutral headquarters in Denmark is testament to this commitment. We listen to and work closely with professionals and users alike as we build on more than five decades of leading research and development in overcoming hearing loss. In our continuous search for unique and clear solutions to complex problems, we strive to give people with hearing loss the same opportunity to communicate as those with normal hearing.*



ReSound® helps people rediscover hearing with innovative products resulting from our commitment to sound quality, design excellence and meaningful solutions. Surround Sound by ReSound™ is the name of our top-rated\*, unique sound processing strategy. Our philosophy is to emulate the function of the natural ear to restore the hearing nature intended us to have.

With it we want sound to be true to the life around you, provide exceptional speech understanding and a good sense of where sounds are coming from. Design is an important part of removing the stigma that prevents people from benefitting from a hearing aid. Our products are beautiful on the hand, and should feel invisible on the ear. Just as important, our design features like iSolate™ nanotech coating make them more robust, and our engineering design produces exceptional performance.

Today opportunities to reach out, access information and interact have multiplied as our world becomes increasingly connected. However, despite decades of innovation in hearing technology, traditional hearing aids don't address the challenge of more and more sounds coming from electronic devices. Our commitment to remove this barrier with the industry's best wireless hearing aids based on 2.4 GHz technology is just one example of a meaningful solution.

### **IFHOH JOURNAL**

The deadline for submissions for the next issue is February 3, 2017.

**Contributions are welcome!**

The preferred length for articles is one page (400 to 500 words). Short and long articles, from 25 to 1,500 words, may also be accepted. News bytes and announcements of coming events are appreciated, including photographs and illustrations. Please send pictures in jpeg format and files as rich text or word documents. Many thanks!

Carole Willans, Editor, *IFHOH Journal*, email: [journal@ifhoh.org](mailto:journal@ifhoh.org)

**Website @ [www.ifhoh.org](http://www.ifhoh.org)**

**Facebook @ [www.facebook.com/groups/IFHOH/](https://www.facebook.com/groups/IFHOH/)**

**The International Federation of Hard of Hearing People (IFHOH)** is an international non-governmental organisation representing the interests of more than 300 million hard of hearing people worldwide. IFHOH is registered as a charitable organisation at Vereinsregister Amtsgericht Hamburg, Germany (Nr. 69 VR 10 527) and is also an International Non-Governmental Organisation having special consultative status with the United Nations' Economic and Social Council (ECOSOC). IFHOH is a member of the International Disability Alliance (IDA) and works closely with the UN system using the Convention on the Rights of Persons with Disabilities as a tool for change.



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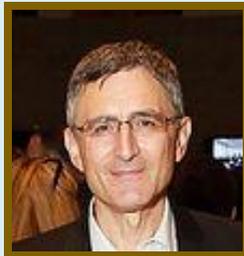
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