

## **DbI Review issue Number 45 • January – June 2010**

Deafblind International was formerly known as the International Association for the Education of Deafblind People.

DbI Review appears twice yearly, the two editions are dated January-June and July-December.

The editor will be pleased to receive articles, news items, letters, notices of books and information on forthcoming events, such as conferences and courses, concerning deafblind children, young adults and older people. Photographs and drawings are welcome; they will be copied and returned.

All written material should be in the English language and may be edited before publication. It should be sent for publication to arrive by the date below.

Opinions expressed in articles are those of the author and should not be understood as representing the view of DbI.

DbI Review is also available on disk. If you are interested in receiving your copy in this format, please contact:

DbI Secretariat

PO Box 143, Burswood

WA 6100, Australia

Telephone (08) 9473 5422

Facsimilie (08) 9473 5499

TTY (08) 9473 5488

Editor

Stan Munroe

Design

Geoff Dunn

Distribution and DbI Membership

DbI Secretariat

DbI Website

Stan Munroe and Secretariat

Editorial Office

CDBA Office, 2652 Morien Hwy,

Port Morien, NS, Canada B1B 1C6

Tel: 902-737-1453

Fax: 902-737-1114

Email: [munroes@seaside.ns.ca](mailto:munroes@seaside.ns.ca)

Website: [www.cdbanational.com](http://www.cdbanational.com)

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## **A message from the president**

Dear friends and colleagues!

Despite the transport problems of the past months caused by weather and ash, DbI was able to be present at various deafblindness related international events.

The DbI Management Committee organised its meeting in São Paulo, Brazil in February. We had the pleasure to meet with the hosts of the World Conference to be held there next year. I hope that many of you will be able to meet there for what I am sure will be a memorable experience.

After Brazil I was invited to a Board meeting of WFDB in Bangkok led by Lex Grandia. I wish to extend to Lex, on our behalf, all the very best wishes in dealing with his health.

In April I participated in a wonderful conference in Melbourne, Australia. All the workshop sessions I attended were of such high quality that they could have, each in its own way, been a key note speech.

The next stop on my travel was Bulgaria, where I attended an executive meeting of the European Deafblind Union (EDBU). I would like to congratulate the Bulgarian National Association of the Deafblind for their achievements over the last years.

In many of the meetings where DbI was present it has been stressed the importance of the UN Convention and the recognition of deafblindness as a unique disability. This is very high on the list of importance in many countries. I wish to congratulate the government of Italy for finally recognising deafblindness in legislation, after many years of promoting this law.

As for the rest of this year it is really satisfying to see the amount of planned activities, including the family meeting in Olomouc, Czech Republic, the Communications Network Course in Paris and the Acquired Deafblindness Network Conference in Aalborg, Denmark. The programmes are of the highest quality and I am sure will stimulate knowledge, networking and friendship.

And finally this is the first Review organised and prepared by our new Information Officer Stan Munroe who I think has done a splendid job getting this together.

Once again, thanks to all who, in whatever manner, are supporting Deafblind International and in consequence deafblind children, adults, families and professionals around the world.

William

## **EDITORIAL**

Dear Friends

First, I would like to introduce myself as the new DbI Information Officer and Editor for DbI Review. The handover from Eileen Boothroyd (Sense UK) to me and the Canadian Deafblind Association (CDBA) took place April 01, 2010. Replacing Eileen will be a very hard act to follow, indeed. But like Eileen, I will be open to materials

coming from all directions about any topic related to deafblindness for the DbI Review.

I hope that you will be pleased with the content in this magazine's edition. Perhaps you might notice the presence of numerous articles from Latin America. While it was intentional to highlight Brazil, considering they are the hosts for the 2011 World Conference, it was an added bonus to have articles from Colombia, Venezuela and the Dominican Republic.

You will be in for a special treat should you attend the 15th DbI World Conference in São Paulo, Brazil, 27 September 27- 01 October, 2011. The Brazilians know how to put on great conferences (which I know from personal experience having the privilege of attending three conferences organized by Grupo Brasil). Like the Brazilian article in this magazine might imply, the success of their conferences has been the result of exceptional organizational networking.

As someone who has observed the world-wide growth of programs during the past 35 years, it is special to see the important progress that is occurring in so many locations around the world. In addition to the Latin American projects, this edition also features several other examples from such developing countries as Lebanon and Romania. I would be remiss if I didn't indicate that the rapid expansion of development in this field is, in many cases, the result of partnerships with such international organizations as Perkins International, Sense International and Christoffel Blindenmission (CBM). To highlight the technical nature of DbI Review, this edition features several important scientific articles and practical articles. Jude Nicholas' article on touch is another welcome neurological work advancing the understanding of people with deafblindness. The scientifically based observations that the tactile abilities of individuals who are deafblind are superior to sighted-hearing people should not be surprising at all!

The article from Royal Dutch Kentalis at Sint-Michielsgestel demonstrates the use computer technology to develop literary for children with deafblindness.

The Swiss have submitted a practical based article describing how SNAB is using ICF, the International Classification of Functioning, Disability and Health in their services to visually and hearing impaired people. This classification system will be a topic at the ADBN Conference in Aalborg Denmark, September 29-Oct 03, 2010. Promoting artistic experiences for people who are deafblind is becoming an important focus. Check out the article on the sensory arts program at Deafblind Ontario Services, Sense Scotland's announcement of their 9th International Helen Keller Award and the reference to a Creative Deafblind Artisans Art Show in Brantford, Ontario, mid-summer, 2011.

In closing, I wish to say that DbI is always welcoming comments and suggestions from the membership about the information program. Perhaps you are aware that DbI is considering a future change in the magazine format, from being print to a web based format. It would be interesting to hear from the readership about this intention. Thanks to everyone who has submitted material. I truly value your support during this transitional period. Your contributions are most important towards continuing to make DbI Review such a great magazine.

Stan Munroe

# **From active touch to tactile communication:**

## **What's tactile cognition got to do with it?**

Although visual and auditory cognition is well researched and better understood, relatively little is known about tactile cognition. Tactile cognition refers to the higher order processing and integration of tactile information through active touch. Recent developments in cognitive neuroscience mean that we now know far more about the mechanisms underlying tactile cognition than ever before.

## **Making sense of our touch**

Touch provides a rich variety of information about the world around us. The sense of touch is the first sense to develop, and it functions even after seeing and hearing begin to fade. Just before the eighth week of gestation an embryo may develop sensitivity to tactile stimulation.

Touch is our most social sense, and it provides us with our most fundamental means of contact with the external world. Interpersonal touch plays an important role in governing our emotional wellbeing.

The sense of touch provides us with an often-overlooked channel of communication. The notion “to touch with fingertips” is very much related to communication as today’s “touch generation”, consisting of a range of software, games, iPods and mobile phones let people connect with each other through interactive experiences. Active touch, also described as haptics, plays a regular and frequent role in our everyday life. Whenever we retrieve keys or lipstick from the bottom of a pocket or purse, or awake at night to switch on a lamp or answer a phone, we must identify by active touch the desired objects as distinct from other objects.

## **Understanding the tactile brain**

It is through the sense of touch we process the tactile information of our environment. Touch messages are the first link in the “chain” of information properties required for the processing of tactile information.

The tactile processing system involves the basic somatosensory pathways and is divided into different central regions and distinct streams of information processing. The somatosensory cortex is involved in processing information related to touch. The somatosensory cortex is located in the parietal lobe of the human brain and receives tactile information from the hand, foot & body. It is well known that a relatively larger proportion of the somatosensory cortex is given over to the representation of the hands than to other parts of the body, given their relative surface area.

The human brain is separated into two distinct cerebral hemispheres, connected by the corpus callosum, and the functions of each cortical hemisphere are different. A study has shown that hemispheric dominance appears to be an organizing principle for cortical processing of tactile form and location; a left hemispheric dominance for tactile form recognition (what one is touching) and a right hemispheric dominance for tactile localization (where one is being touched) (van Boven et al., 2005).

Interestingly, a left-hemisphere advantage for processing local spatial details and a right hemisphere advantage for processing global spatial has been similarly described in the visual system.

Furthermore, a neuroimaging study found that during tactile-based spatial processes, areas traditionally associated with both visual imagery and visual perception were activated (Ricciardi, et., 2006). This means that both tactile and visual stimuli lead to similar patterns of neural activation, supporting the view that there is a common spatial map accessible by means of either tactile or visual sensory modality.

”Touch to emotion”: neural correlates of the emotional aspects of tactile processing  
We use touch to share our feeling with others, and to enhance the meaning of other forms of verbal and non-verbal communication.

In the case of emotions, it is not our hands but the body, which is crucial to emotional experiences. Given the apparent relationship between bodily-tactile information processing and emotion, it is not surprising that recent neuroscientific research have found evidence for strong neural connections between the somatosensory cortex and the brain regions involved in the processing of emotions; the limbic system.

The limbic system is a set of brain structures including the hippocampus and amygdala, which support a variety of functions including behavior, long term memory and emotion.

While the mechanisms remain unclear, there is evidence for a strong connection between emotion/emotional awareness and tactile-bodily cognition. Thus, it is important to consider emotions as a powerful motivator to tactile learning.

## **Understanding tactile cognitions**

In the last decade there has been a dramatic increase in the number of research studies directed at studying the different concepts of tactile cognition. From these studies, a brief description of the concepts are given below.

Tactile short-term memory can be described as the capacity for holding a small amount of tactile information in mind in an active, readily available state. Visual and auditory short-term memory is said to hold a small amount of information– from about 3 or 4 elements (i.e., words, digits, or letters) to about 9 elements: a commonly cited capacity is  $7 \pm 2$  elements, referred as the magic number. Research has shown that the span for serially presented tactile stimuli is similar as in vision (Heller, 1989).

The term working memory refers to a brain system that provides temporary storage and manipulation of the information necessary for such complex cognitive tasks as language comprehension, learning, and reasoning.

The tactile working memory refers to the ability to hold and manipulate tactile information for short periods, which is the transformation of information while in short-term memory storage.

Working memory allows us to hold the tactile stimulus characteristics on-line to guide behaviour in the absence of external cues or prompts. Without active working memory, initial tactual precepts’ may decay quickly.

Studies investigating the neural basis of working memory have shown that the prefrontal cortex (the frontal system of the brain) becomes active while subjects perform working memory tasks, either in the visual or in the auditory modality.

Tactile learning is the process of acquiring new information through tactile exploration. Research studies of tactile information processing in humans have shown that people can be trained to perceive a large amount of information by means of their sense of touch.

On the basis of numerous studies it is suggested that the processing of active touch, understood from an information-processing approach, is a fully functional cognitive system.

## **Tactile cognitions in the deafblind: From active touch to tactile communication**

People who are deafblind use active touch in ways that no one else does to explore objects and the environment, to perceive feelings and to act and communicate. They use many different methods of communication. The method chosen will depend upon the amount of residual sight and hearing and the age of onset for the vision and hearing loss (congenitally or adventitiously deafblind).

There are various tactile communication and tactile language interventions, which are used within the deafblind field, such as haptic communication, full co-active signs, one hand coactive signs and hand-over-hand signing. Recently there has been an interest in understanding the cognitive aspects involved in these tactile communication methods.

When you cannot see or hear things clearly how do you perceive or share your feelings? The sense of touch provides a very powerful means of eliciting and modulating human emotion (Gallace & Spence, 2008).

However, when hearing and vision are limited, emotional interactions occur in a world of physical closeness and one requires skills to perceive and share feelings by active touch. Therefore, it is important to consider emotions as a powerful motivator to tactile learning.

Deafblind individuals are generally more experienced in recognizing stimuli by active touch. What is the impact of combined vision and hearing impairment on tactile cognitions? Can studies with persons with deafblindness help us understand tactile cognition such as tactile working memory, tactile information processing speed or tactile memory?

Working memory tasks include the active monitoring or manipulation of information or behaviors. A study investigating the tactile working memory ability of an adventitiously deafblind woman found higher average performance level in a tactile memory span test compared to performance on both visual and auditory memory span tests (Nicholas & Christensen, in press).

The tactile memory span test measures tactile forward memory and tactile backward memory. Tactile forward memory span is the longest number of items that a person independently touches to the complete series of objects in the correct order. Tactile backward memory span is a more challenging variation which involves independently touching the complete series of objects in the correct reverse order. Tactile forward memory is thought to be related to the efficiency of attention, whereas tactile reverse memory is thought to be associated with working memory.

Working memory refers to a cognitive system that allows us to actively maintain and manipulate information in mind for short periods of time. This system plays a critical role in many forms of complex cognition such as learning, reasoning, problem solving, and language comprehension.

Working memory for visual sign language indicates similar systems irrespective of access to auditory information and preferred language modality (Rudner, et. al., 2009). The structure of working memory for sign language is highly similar to working memory for spoken language (Wilson & Emmorey, 1998). This evidence suggests that the structure of working memory for language develops in response to

language input regardless of the modality of that input, thus resulting in largely the same architecture across spoken and signed languages (Wilson & Emmorey, 2003).

### **Tactile information processing speed**

Results from a neuropsychological investigation showed that an adventitiously deafblind person took significantly lesser time to feel and remember objects on a Tactile Form Recognition test (Nicholas & Koppen, 2007). This increased tactile processing speed could reflect how efficiently the person's attention system was functioning and may seem that a combined auditory and visual deprivation may alter the speed of response

to tactile stimuli. Furthermore, results from this study also showed superior performance in tactile memory for the location of objects on tactual performance tests. Neuroplasticity is the capacity of the nervous system to modify its organization. The issue of neuroplasticity is important to the deafblind field since sensory deprivation is commonly seen within the deafblind population.

Taken as a whole, the results of these two studies indicate that deafblind individuals perform more effectively than sighted-hearing people on tasks of tactile working memory and tactile memory. A possible explanation for the better performance is that deafblind individuals are expected to have more tactile experience since this is the sensory system that they must rely on for information about their environment.

In other words (tactile) practice makes perfect. The deafblind person can recognize an object by feeling a portion of it, which then acts as a signal for the whole image; a brief touch of the object would be enough to prompt full recognition (Meshcheryakov, 1974).

Further to this, the performance of ten deafblind and ten sighted-hearing participants on four tactile memory tasks was compared. Results showed that the deafblind person's encoding of tactile spatial information is more efficient than that of sighted-hearing people. The explanation given for the superior tactual performance of the deafblind people was that it was a product of more tactual experience. This view appears to be consistent with Rönnberg's (1995) claim that compensation of a deficit by means of unrelated cognitive functions (neuroplasticity) rather than perceptual compensations accounts for the improvement in performance seen in deafblind individuals in different tasks.

### **Which neural networks are involved in tactile language processing when hearing and vision are lost simultaneously?**

A study which compared neural activation during tactile presentation of words and non-words in a postlingually deafblind subject and six 'normal' volunteers, found that the tactile language activated the language systems as well as many higher-level systems of the postlingually deafblind subject. This means that tactile languages are equipped with the same expressive power that is inherent in spoken languages.

Finally, it should be noted that the understanding of tactile cognitions is needed in the functional assessment (tactile strengths & weaknesses) of deafblind individuals. The outcomes of an assessment of tactile sensation, perception and cognition, in addition to "embodied experiences" and "bodily-tactile emotions", can be used as a basis for intervention or intervention planning. However, the assessment should take into account whether the individual has congenital or acquired deafblindness.

The tactile demands the deafblind person has to meet in its environment can serve as a starting point for understanding tactile cognition. When assessing the person with acquired deafblindness, structured interviews, adapted psychometric instruments or checklists measuring the tactile prerequisites of every-day activities could be applied. Furthermore, it is possible that the understanding of tactile cognition could help them to be more conscious of one's tactile-bodily awareness.

However, when assessing the tactile processing abilities of congenital deafblind individuals, an interdisciplinary integrated assessment is necessary. One should utilize a collaborative team approach and consider the assessment in a dynamic and broader context. This means recognizing ecological and communicational aspects and emphasizing a tactile cognitive assessment approach in day-to-day communication. Communication is a form of interaction in which meaning is transmitted by the use of signals that are perceived and interpreted by the partner. In the case of deafblindness, this involves the transfer of information by bodily-tactile means. The functional assessment of the congenital deafblind person must be person-guided and involve careful observation and interaction, across environments, learning areas and recreational settings. The assessment should also include the attributes of tactile sensory processing, tactile motor functioning, tactile perceptual processing and especially tactile cognitive processing. The fundamental cognitive capacity of the deafblind person should be understood in terms of tactile cognitions (Nicholas & Frölander, 2009)

Children who are deafblind often use their own unique tactile communication signals, such as movements, muscle tension, postures, and gestures, which may be missed or misunderstood by parents or caregivers.

This difficulty with interactions and tactile (communicational) deprivation over a long period can cause emotional, behavioral and relational problems. Thus, they may become passive and withdrawn, show signs of tactile defensiveness or develop self abusive or aggressive behaviors. For instance, lack of communication skills due to deafblindness may be a contributory factor for the behavioural difficulties seen in CHARGE Syndrome (Nicholas, 2005). Harmonious interactions and mutual sharing of emotions, often done through movement and active touch with children who are deafblind, are essential for the development of tactile communication (Janssen et. al., 2003). It is also an important step in the path to prevent the development of "challenging" behaviors. Thus, the theoretical and clinical understanding of the emotional aspects of active touch and tactile communication is needed in the deafblind field.

By studying the cognitive and emotional aspects of tactile communication of deafblind persons, future research may find answers to some of the following questions; what is the connection between dual sensory impairment and tactile defensiveness; what is the relationship between tactile working memory abilities and the use of linguistic constructions in tactile communication or tactile language; how are the 'autobiographic' forms of tactile memory established; how will tactile memories deteriorate over time compared to visual and auditory memory and how does emotion influence tactile cognition?

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Author

Jude Nicholas, PhD. Resource Center for the Deafblind and Haukeland University Hospital, Bergen, Norway.

The article is abridged from the full report which is available on the website [www.dovblindfodt.dk](http://www.dovblindfodt.dk).

# **Conference**

## **First Announcement**

### **XV Deafblind International World Conference**

#### **Bourbon Convention Ibirapuera**

#### **São Paulo City, Brazil**

#### **27th September – 1st October, 2011**

GRUPO BRASIL, a consortium of organizations that provide services to deafblind people in Brasil, and ADEFÁV, a resource center, is pleased to announce they are hosting the 15th Deafblind International World Conference on Deafblindness in São Paulo Brazil, September 27 through October 01, 2011.

Inclusion for a lifetime of opportunities – has been selected as the theme for this conference.

This theme carries forward the theme of the last World Conference in Perth Australia (2007) which was titled ‘World Wide Connections – breaking the isolation’.

The theme ‘Inclusion for a lifetime of opportunities’ will explore options for people who are deafblind to develop relationships with their family members, their friends, their schools or colleges and those professionals working closely with them.

The conference will review and analyse situations that not only connect deafblind people with one another but enable the development of their best potential together with achieving their independence.

This is seen as a great opportunity for Latin America to share its own experiences with the rest of the world and to highlight the special needs and issues of the Brazilian context. In a sense, this will be seen as a DbI Conference with the face of Latin America.

Venue:

#### **Call for Papers**

The Conference Scientific Committee wish to invite people representing all facets of deafblindness to submit abstracts for the open workshops and poster sessions that will take place during the conference. A number of special focus areas to fit the theme are being suggested, which include inclusive education, assistive technology, advocacy, transition to adult life etc.

The Scientific Committee has developed an information package which will be available from the website in October 2010 for anyone interested in presenting a paper or poster session.

Check out the website at [www.dbi2011.com.br](http://www.dbi2011.com.br)

## **PERKINS INTERNATIONAL: Where in the World is Perkins?**

Lina Sabbagh came to Perkins Educational Leadership Program to be immersed in educational techniques for children who are deafblind.

After nine months observing educators and working with students in Perkins Deafblind Program, Sabbagh returned to the Lebanese School for the Blind and Deaf to take a lead role in the establishment of a program for children who are deafblind. Today Sabbagh uses the teaching strategies she learned at Perkins to foster communication skills in her students.

“Going into Perkins, I thought that deafblind children were incapable of completing anything,” Sabbagh recalled. “Throughout the year I was surprised to see how [Perkins students] progress and gain new skills.”

Lina Sabbagh started out as an art teacher at the Lebanese School for the Blind and Deaf before advancing to a full-time classroom. The school’s director, Wadad Lahoud, had studied in Perkins Educational Leadership Program during the 1950s, at a time when the Lebanese school served students who were deaf or visually impaired but did not yet cater to students who were deafblind.

Seeing Sabbagh’s innovation with students and commitment to teaching, Lahoud recommended her for the ELP – convinced that with the right kind of experience, Sabbagh might institute deafblind instruction at the Lebanese school.

When she came to Perkins campus in 2007, Sabbagh immersed herself in practicing tactile finger spelling and sign language, learning braille and in finding new ways to communicate with students who are deafblind.

Through her studies and work with students in Perkins Deafblind Program, Sabbagh discovered new strategies for communicating with students who are deafblind. Since returning to the Lebanese school, Sabbagh has included these and other practices with students in the school’s new deafblind program.

“The first method I applied was the calendar [box] system. I gave the child two boxes, one for the beginning of the activity and a second for the end. I would put the tool s/he needed to complete this activity in the first box. When s/he is done, s/he would put what s/he did in the second box,” Sabbagh explained.

The calendar box introduces the key element of teaching time frame and anticipation to children who are deafblind. An object that represents an activity, i.e., a spoon meaning “mealtime” is placed in a box to the child’s left. When the student is guided to the left-hand box, s/he feels the object and the teacher makes the sign identifying an activity. After completing an action, s/he places the object in the “finished” box on the right. This technique helps a student without sight or vision to understand time and establishes pre-literate left-to-right interpretation of signals so fundamental to learning to read.

Beyond strategies and tactics, Sabbagh says, “I learned that I must believe in my students, and that the more effort I put into teaching them, the more I will learn from them.”

Sabbagh continues to take the lead from her students, using an individual approach to match their abilities and interests.

“I observe what they do to know on which level to communicate with them,” Sabbagh says. “I now see that deafblind children are capable of doing anything as long as they are taught properly.”

Reprinted from Perkins School for the Blind  
175 North Beacon Street, Watertown, MA, 02472

## **Conferences**

### **Bridges – connecting people:**

The 8th Conference of the Acquired Deafblindness Network, 29 September – 3 October, 2010

City of Aalborg, Denmark

Using this theme the conference will explore notions of developing relationships between people with deafblindness, families, friends and professionals. Bridges not only connect people but enable movement and development, independence and growth of potential.

Among the conference topics are dementia and deafblindness, haptic communications, practical use of ICF (International Classification of Functioning) in deafblindness, relations in families with deafblindness, and much more.

The conference language will be English.

Registration

Deadline for final registration: 31 July 2010

All conference registrations and hotel bookings must be made online through the conference website: [www.dbcent.dk/adbn2010](http://www.dbcent.dk/adbn2010)

Preliminary Conference Program details

are also available on the conference website. For any questions about the conference program, registration or accommodations, contact [adbn2010@cfed.dk](mailto:adbn2010@cfed.dk).

### **The 10th International CHARGE Syndrome Conference for Families and Professionals**

[Friday – Sunday, July 29-31, 2011]

and 2nd Professional Day [Thursday, July 28, 2011] at the Rosen Shingle Creek Resort, Orlando, FL

Call for platform presentations, poster presentations, exhibits, demonstrations, and on-site research projects

Deadline for Submission: November 1, 2010

Marilyn Ogan and Janet Murray 2011 Program co-chairs

The CHARGE Syndrome Foundation, Inc. 141 Middle Neck Rd. Sands Point, NY 11050

If you have questions about the program, email them to:

[marilyn@chargesyndrome.org](mailto:marilyn@chargesyndrome.org) or [janet@chargesyndrome.org](mailto:janet@chargesyndrome.org)

## **B in CHARGE conference**

8–10 October, 2010

Fremantle, Western Australia

Anazing CHARGE children

Shining brighter as they grow

[www.chargesyndrome.org.au](http://www.chargesyndrome.org.au)

8–10 October, 2010

Esplanade Hotel Fremantle WA

[www.esplanadehotelfremantle.com.au](http://www.esplanadehotelfremantle.com.au)

## **SOCIEVEN, Deafblind of Venezuela: 15 Years**

January 20, 2010 marked our 15th anniversary as an organization. This is a perfect moment to make a retrospective of our achievements and evolution as an organization. SOCIEVEN, Deafblind of Venezuela, is a non-profit association founded in 1995 by María Luz Neri de Troconis. As a member of Deafblind International (DbI), SOCIEVEN aims to improve communication skills and quality of life for deafblind people and their families.

In 1995, the disability deafblindness was generally unknown throughout the country. Through great efforts we have reversed this lack of awareness and have succeeded to develop an effective support program. We are pleased to say that we have developed an organization that now manages four important programs for deafblind people in Venezuela. They include: the national network and community program; training and consultancy services for parents, professionals and institutions; awareness of deafblindness and usher syndrome and the Five Senses in Action Program.

Deafblindness has grown to be better known, in a positive way, in Venezuela. People who are deafblind are now being understood as people who, even though they do not see or hear (although some have residual vision and hearing), have the possibility of communicating through different systems. Even more important, these disabled people now have a greater potential to become better integrated in society.

During the last fifteen years, SOCIEVEN has registered numerous achievements. It has identified 678 people of all ages, with acquired and congenital deafblindness. Some 465 of these individuals are supported by Socieven in various ways. The organization has trained 3,320 professionals, parents and students belonging to special institutions operated by the Department of Education in 16 states. SOCIEVEN's goal for 2015 is to identify and ensure that appropriate services are available for the estimated 4,000 people who are believed to be deafblind in Venezuela.

It is important to highlight that our collaborators are an essential part of SOCIEVEN'S goals that strive towards ensuring that people who are deafblind in Venezuela have a better quality of life. We now have a group of almost 1,000 ambassadors (artists, athletes, social communicators, businessmen, photographers, etc); intervenors for deafblind people; professional volunteers; representatives from partner companies, institutions, state agencies and the media who have supported us from the first moment that we decided to make the public aware of deafblindness.

SOCIEVEN is going to celebrate its anniversary throughout the entire year 2010 through a number of wonderful initiatives.

The organization started off 2010 with the publication of the “Guide to Support Deafblindness” with the assistance of the Polar Foundation. This guide is the first Venezuelan publication designed to inform and provide simple tools for family members and professionals working with the deafblind population. The guide is available on Socieven’s website in Spanish.

SOCIEVEN will initiate the Masters Degree ‘Specialization in Deafblindness and Multiple Disabilities in Venezuela’ at the Liberador Pedagogical Experimental University. This course is supported by Perkins International, Christoffel Blindenmission (CBM) and International Council for Education of People with Visual Impairment (ICEVI).

SOCIEVEN also created the Genetic Laboratory for people with Usher Syndrome at the University of Orient Venezuela located in the state of Nueva Esparta. This was achieved thanks to the Organic Law of Science, Technology and Innovation. This program is also supported by the Real Estate Securities Fund of Venezuela and the OFL Corporation.

Our calendar ‘Five Senses in Action 2010’ (created by Tactus Production) with the actress Elba Escobar and a congenital deafblind child, Yuralbis Contreras, on the cover, continues to raise awareness about deafblindness. At the same time, this calendar promotes the teaching of braille, manual alphabet and fingerspelling (dactylogologic) as communication options for deafblind individuals.

We extend thanks to Tactus Pro and Infocus Production for a special gift helping us to celebrate 15 years. They have produced a beautiful documentary that explains our work through images and testimonies. Check us out through the following link:  
<http://www.youtube.com/watch?v=j4DjfCP2vPo>

We have to extend a special thanks to the participation of Anabella Troconis during these past 5 years. Actress, producer and leader of the Deafblind Ambassadors, and creator of the “Five Senses in Action” program, Anabella’s philosophy is: “the vision and hearing of the artist; the touch and sense of smell of deafblind people.”

We begin the year of our anniversary full of joy and strength; beginning the year committed to the mission of improving the communication abilities and quality of life for people in Venezuela who are deafblind. This report is a great opportunity to express our gratitude to all the staff who has been a part of SOCIEVEN; to the national and international institutions (Perkins International, CBM, ICEVI, Sense, ONCE, Birmingham University, CDBA, ULAC and others) that have supported us through all these years; to the professionals who we work closely with in our programs; to our many volunteers and collaborators; to the Latin-American region, and finally to our clients, this special population of people, and their families, that we have assisted and will continue to do so.

Maria Luz Neri de Troconis  
SOCIEVEN Director

[www.Socieven.org](http://www.Socieven.org)  
[www.cincosentidosenaccion.blogspot.com](http://www.cincosentidosenaccion.blogspot.com)

## **Sense International (Romania)**

### **together with Deafblind people in Romania**

With the financial support of International Women's Association from Bucharest, Sense International (Romania) equips the Emergency Hospital Sf. Pantelimon screening device to test the hearing of newborn babies. The device, worth approximately 10,000 Euro, will ensure the screening of around 2,000 babies each year.

On March 20, 2010, the medical staff from the Neonatal Unit was trained in testing the hearing of babies, by Dr. Alexandru Pascu – ENT/audiology specialist, PHD in medical sciences and researcher of the “Prof. Dr. Dorin Hociota” Medical Center for Phono-Audiology and ENT Functional Surgery.

“An optimum and efficient hearing screening programme for newborn babies will allow the early identification (in the first month of life) of permanent bilateral hearing impairments. An objective diagnosis can be given by the age of 3 months, while an adequate therapeutic intervention (prostheses or cochlear implant) can be done by the age of 6 months. This way, the child is given the best chances for a normal acquisition of information and normal development of language” Dr. Alexandru Pascu.

Sense International (Romania) continues implementing the Early Intervention programme, providing babies and young children with visual and/or hearing impairments the chance to benefit from diagnosis, rehabilitation and early intervention. The programme is developed in partnership with national and local authorities, kindergartens and schools, with the support of multidisciplinary teams consisting of doctors, special education teachers, psychologists and parents.

After the initial hearing screening, SI(R) has an active role in providing solutions for the problems identified. Therefore, the children diagnosed with sensory impairments begin an individualized rehabilitation programme within the Early Intervention Support Centres developed by SI(R) in Bucharest, Oradea and Timisoara.

The positive outcomes of this programme in 2009 consist of 6,564 newborn babies having their hearing and/or vision screened (in Obstetrics – Gynaecology Clinical Hospital Prof. Dr. Panait Sarbu in Bucharest, Obstetrics – Gynaecology Clinical Hospital Dr. Ioan Cantacuzino in Bucharest Obstetrics – Gynaecology Clinical Hospital Oradea and Obstetrics – Gynaecology Clinical Hospital Dumitru Popescu in Timisoara).

About Sense International (Romania) – SI(R) is a nongovernmental, nonprofit organisation, with no political affiliation, independent of private or public institutions. SI(R) was established in 2001 and, for almost 10 years, it has developed many programmes to support deafblind people in Romania. SI(R) mission is to work in partnership with others – deafblind people, their families, carers and professional – to ensure that everyone facing challenges because of deafblindness has access to advice, opportunities and support.

The active involvement of Sense International (Romania) in providing support to deafblind people and the excellent results of its programmes gained SI(R) two important distinctions in 2009, as part of ERSTE Foundation Awards for Social Integration – the Recognition Award and the Practitioners' Award.

## Country News

Australian DeafBlind Council (ADBC) has a new email address, [info@deafblind.org.au](mailto:info@deafblind.org.au) and telephone number 03 9882 8596.

### **National Companion Card**

The National Companion Card Scheme was officially launched on 3 December last, International Day of People with Disabilities, and the website is now live at <http://www.fahcsia.gov.au/sa/disability/progserv/people/companioncard/Pages/default.aspx>.

The National Companion Card Scheme enables people with disability dependent on full-time care to take a carer with them on transport and to sporting and entertainment events for the price of a single ticket. More than 2700 businesses are supporting the Companion Card including the AFL, Basketball Australia, Tennis Australia, the Australian Chamber Orchestra, Reading Cinemas, Circus Oz, Fitness First Australia, Circus Royale, Event Cinemas and the Australian Ballet.

### **New Disability Employment Services Announced:**

Successful organisations for the Australian Government's new \$1.2 billion Disability Employment Services program, which began on 1 March 2010, were announced in December last. One of the significant changes is the removal of the cap on the number of people who can access help. There will be 66 organisations from more than 1100 sites delivering Disability Employment Services Program A, which is for job seekers with disability, injury or health condition who require assistance but are not expected to need long-term support in the workplace. A list of successful organisations by Employment Service Area for 2010-2012 is available at <http://www.workplace.gov.au>.

### **Inquiry into ageing and disability**

The Australian Senate Community Affairs References Committee will inquire into access to planning options and services for people with disability to ensure their continued quality of life as they and their carers age. The inquiry also aims to identify any inadequacies in the choice and funding of planning options currently available to people ageing with disability and their carers. The Committee is seeking written submissions by 28 May 2010 for report by 2 September 2010. For more information, visit

[http://www.aph.gov.au/Senate/committee/clac\\_ctte/planning\\_options\\_people\\_ageing\\_with\\_disability/index.htm](http://www.aph.gov.au/Senate/committee/clac_ctte/planning_options_people_ageing_with_disability/index.htm)

### **Disability Investment Group report**

The Disability Investment Group report, 'The Way Forward: A new disability policy framework for Australia', has been released as part of the Australian Government's commitment to set out a ten-year plan for coordinated, across-government action for Australians with disability. With the number of people with a severe or profound disability predicted to rise to 2.3 million by 2030, the Government is looking at how



to better support people with disability over the long-term. The Government has already responded to the report's primary recommendation by announcing that the Productivity Commission will undertake a comprehensive feasibility study into a national disability insurance scheme. The report and membership of the Disability Investment Group can be found at [http://www.fahcsia.gov.au/sa/disability/news/Pages/disability\\_investgroup\\_report.aspx](http://www.fahcsia.gov.au/sa/disability/news/Pages/disability_investgroup_report.aspx)

## **Greater Access to DVDs for Australians with Vision or Hearing Impairment**

The Australian Visual Software Distributors Association (AVSDA), representing the home entertainment film and TV industry, has announced that all the major film distributors, and some smaller Australian independents, have committed to make available audio description and English captioning on the majority of theatrical films when released on DVD.

The distributors making this commitment include: Disney Studios Home Entertainment; Hopscotch Entertainment; Madman Entertainment; Paramount Home Entertainment; Roadshow Entertainment; Sony Pictures Home Entertainment; Twentieth-Century Fox Home Entertainment; Universal Pictures Video and Warner Home Video. One distributor that hasn't agreed to increase captioning or audio description is 21st Century Pictures (it does not appear to be an AVSDA member).

Disability groups representing vision and hearing impairment have been lobbying for a commitment from distributors to improve media access features on DVDs and follows the development of the AVSDA Accessibility Framework for the Home Entertainment Film Industry and labelling standards developed in conjunction with the Human Rights and Equal Opportunity Commission (now Australian Human Rights Commission) in 2007.

The announcement means that the major home entertainment film and TV distribution companies operating in Australia have committed to ensuring that the majority of theatrical films when released to standard definition DVD, will contain both audio description and English captioning or subtitles. Significantly, this commitment also meets the Australian Government's desire to ensure that DVDs distributed in Australia 'include captions and audio description, where these are already available'.

This announcement does not apply to non-studio or acquired films distributed in Australia as these films and the DVD features therein are out of the control of the distributor.

The AVSDA Accessibility Framework for the Home Entertainment Film Industry and labelling standards can be viewed at <http://www.avsda.com.au/dvdaccess.asp>.

## **Adelaide Festival produces Australia's first audio-described spectacular**

The 2010 Adelaide Festival last February hosted the first Australian outdoor spectacular to be audio described. Its Artistic Director, Paul Grabowsky, said he was

delighted to have made the opening festival event- A Little More Light more accessible to people with a disability. The audio description enhanced the live experience, giving visual details of the performance by “Groupe F”, who lit up the 2004 Athens Olympics and the 1998 French World Cup.” By bringing a portable radio and tuning to Radio Adelaide 101.5FM, audience members could listen to a description of the visual aspects of the free performance. This event resulted from the successful collaboration between the Community Arts Network (CAN SA), Disability & Arts Transition Team (DATT) and the Adelaide Festival. The Adelaide Festival access initiative included Auslan interpreted events, a sur-titled production of Le Grand Macabre, wheelchair access at all venues, and Assistive Listening Devices (audio loops) for hearing aid users installed at specific theatre venues.

## **Human Rights Commission requests further information from cinemas**

The Australian Human Rights Commission is currently assessing an application from Hoyts, Greater Union, Village and Reading cinemas for a temporary exemption from requirements of the Disability Discrimination Act in relation to captioning and audio description while they expand the current accessible circuit from 12 to 35 cinemas.

What is DiVine? DiVine (<http://www.divine.vic.gov.au>) is a new website written by and for people with disability and published by the Victorian Government’s Office for Disability. DiVine aims at informing, engaging and entertaining. It is a vibrant, inclusive community that encourages participation. It gives the opportunity for people to learn from each other and have fun at the same time.

## **Access to aviation**

The first-ever comprehensive White Paper ‘Flight Path to the Future’ (<http://www.infrastructure.gov.au/aviation/nap/index.aspx>) brings together all strands of aviation policy into a single document providing planning, regulatory and investment certainty for the Australian aviation industry to 2020 and beyond. Through the work of the Aviation Access Working Group (AAWG), <http://www.infrastructure.gov.au/aviation/aawg/>, on which National Disability Services (NDS) and the Australian Blindness Forum (ABF) are represented, the White Paper recognises the significant difficulties faced by passengers with disability. The AAWG, which has met regularly since February this year was consulted on the new guidelines for airport security screening operators; allocation of emergency exit row seating; simplifying pre-flight processes for the safe carriage of an assistance animal in an aircraft cabin. The AAWG was also consulted in-depth on the Disability Access Facilitation Plan scheme which will see airlines and airports better communicate their efforts to achieve disability access. The Australian High Commission has called on the government to set up a process for the voluntary lodgment of the plans by mid 2010.

## **Conferences**

Australian Orientation and Mobility Conference

The 4th Australasian Orientation and Mobility Conference (AMC2010) will take place between 24-26 November 2010, and hosted by Guide Dogs NSW/ACT at The Women's College within the University of Sydney.

This is a conference for the professional development of Orientation and Mobility specialists, including Guide Dog specialists and those with an interest in vision impairment. Invitations for the submission of abstracts are now open.  
More information at: [http:// www.guidedogs.com.au/amc2010](http://www.guidedogs.com.au/amc2010)

South Pacific Educators in Vision Impairment (SPEVI) Conference 2011 will be held in Sydney from 16 to 21 January 2011. The call for papers will go out later this year. In the meantime, for more information, contact Tricia d'Apice at the RIDBC Teleschool by phoning 02 9872 0332 or emailing [tricia.dapice@ridbc.org.au](mailto:tricia.dapice@ridbc.org.au).

# LISTEN TO ME 5

Conference for deafblind people and their families



27. 7.–1. 8. 2010

OLOMOUC  
CZECH REPUBLIC



The proud host  
of the 5th Listen to Me conference is ZÁBLESK – the association of parents and  
friends of deafblind children, CZECH REPUBLIC

The conference provides an excellent opportunity for the delegates to share their  
experience, obtain essential information and meet new friends via workshops,  
presentations, excursions and other activities. Delegates have a chance to explore  
and soak up the culture and traditions of the Czech Republic and especially the  
Morava Region, where the conference is held.

[www.zablesk.olomouc.com](http://www.zablesk.olomouc.com)

The 8th National Deafblind Conference was held during Wednesday 28th April to  
Friday 30th April and attracted over 300 delegates from around Australia and  
overseas, including people who are deafblind, carers, family members, State and  
Federal Government Officials, disability/deafblind industry groups and suppliers and

other professionals working in the field of disability support services. Able Australia hosted the conference in conjunction with the Australian DeafBlind Council.

The conference was a massive success with a variety of topics being presented by a range of experts which proved extremely insightful and were all aimed at ultimately improving the quality, breadth and ongoing development of services provided to deafblind people. Many ideas, issues, directions and solutions were discussed and debated over the three days. Delegates were also treated to a Masquerade Ball which gave everyone a chance to mingle and get to know one another in what was a great night for all involved.

The conference concluded with members of the deafblind community participating in one of two recreational activities; a river cruise up and down the Yarra or a visit to Pantan Hill Winery. A great way to cap off a progressive, educational and inspiring few days.

Thank you to all who attended and made the 8th National Deafblind Conference one to remember and such a great success!!

### **Raffle 56 Winner!!**

Allan and Tum Smith from Merbein were the lucky winners of Raffle 56's first prize – a brand new Volkswagen Golf 90TSi.

The couple have never won anything before and as expected were ecstatic when they found out the good news. Mr Smith will have the pleasure of driving the Volkswagon all the way home to Merbein. A fantastic opportunity to test out the new car!

Our raffles are another way Able Australia is raising much needed funds to improve the lives of the people supported through our services and programs.

By supporting our raffles you directly add value and enjoyment to the lives of the people we support. Plus, of course, you might win a new car!

## **Canada**

### **Anniversaries**

The Canadian Deafblind Association (CDBA), formerly the Canadian Deafblind and Rubella Association, is celebrating its 35th anniversary this year. Started by a group of parents whose children attended the W. Ross Macdonald School in Brantford (Ontario), the organization has evolved to become a pan-Canadian service delivery and advocacy organization serving primarily individuals with congenital deafblindness.

For those unfamiliar with CDBA, its organization comprises a National office and six autonomous Chapters. The National office is responsible for membership, communications, international relations, national policies and liaison and a variety of different projects such as the "Rubella Study", and the Intervenor Competency document. The Chapters (New Brunswick, Ontario, Manitoba, Saskatchewan and British Columbia) provide service delivery functions, including intervention services and the management of independent residences, as well as information and advocacy activities in their respective provinces. The Chapter activities are supported by funding from the social services agencies of each of the provinces.

Another milestone worthy of mention was the Lions McInnes House – Group Home for Deafblind Persons (Brantford) 25th anniversary celebrations this past June. This was the first home of its kind providing intervention services in the community for individuals with deafblindness. The first facility was a pilot program serving up to 9 individuals before its new larger capacity building became a reality 10 years ago. As a pilot program in Canada, Lions McInnes House was the seed for a network of small community based facilities located throughout Canada.

### **Deafblind Awareness**

Various deafblind awareness events are staged throughout June to celebrate Deafblind Awareness in Canada. The largest marquee event is Junefest ([www.junefest.ca](http://www.junefest.ca)), organized by Rotary Cheshire Homes and the Canadian Helen Keller Centre in Mel Lastman Square, Toronto, Ontario. Another awareness event is the Creative Deafblind Artisans art show organized by the Ontario Chapter for display in Brantford (Ontario), June 11-July 25, 2010.

### **Spirit of Intervenors Symposium**

The 2010 edition of the “Spirit of Intervenors” Conference was held in Toronto at the Sheraton Centre Hotel. It was a huge success, with over 350 attendees during the 4 day symposium from February 24th-27th.

This year’s symposium was themed “Sharing the Torch of Knowledge” and tied in to the Winter Olympics held in Vancouver.

Among the numerous presenters were key note speakers Russ Palmer and Riita Lahtinen from Finland.

The symposium featured the official name-launching party (for the Ontario Chapter and CDBA in general) with cookies, hot chocolate, an ice sculpture and skating at Nathan Phillips Square in front of Toronto’s city hall. The cookies were an especially memorable moment because attendees munched on R shaped cookies to symbolically eat the letter R out of our old name, CDBRA. A name change has never tasted so good!

### **Canada ratifies Treaty**

Since March 11, 2010, Disability groups in Canada have been celebrating the historic ratification of the UN Convention on the Rights of Persons with Disabilities. This is Canada’s declaration that disability (including deafblindness) is now recognized as a matter of fundamental human rights. This is significant for Canada in that it binds our provincial governments, who are responsible for social services, to its implementation.

## **Romania**

## **Early intervention programme**

Sense International (Romania) has extended the Early Intervention Programme to Timisoara. From October 2009, the Early Intervention Support Centre in the School Centre for Inclusive Education “Constantin Pufan” Timisoara opened the doors to welcome new beneficiaries. The multisensory stimulation room and the parents’ counselling room are fully equipped.

A multidisciplinary team has also been brought together, consisting of professionals in the fields of education, health and social services. They will work with the beneficiaries: newborn babies, small children “at risk”, as well as with their parents. Extending the early intervention programme to Timisoara was possible thanks to the generous support of James Tudor Foundation from Great Britain.

Gabriela Jianu, psychologist, national trainer in deafblindness and coordinator of the early intervention team in Timisoara, said: “The specific needs of the children included in the early intervention programme created the necessity to develop a centre where pleasant sensory stimulation activities may be organised in a secure relaxing environment.

The multisensory stimulation therapy, encouraging exploration, motion, socialisation and active learning, makes interaction between the child and the therapist possible. This way, the child is able to control the environment and to make his/her own choices. Therefore behaviours such as autostimulation, stereotypical behaviour, aggressiveness and anxiety are greatly reduced. For relaxation, we use the water bed, music therapy and aromatherapy. For visual stimulation purposes, we use bubble columns, UV lamps, mirror balls, projectors, LED lamps, fluorescent toys and lights. As far as hearing stimulation is concerned, we use musical instruments, sound making toys and an audio system with detachable speakers. We have also created a Resonance Board and the Little Room, adapted after Lilli Nielsen’s Little Room.

The Resonance Board stimulates the children’s ability to react to noise and differentiate vibrations, developing their ability to localise the noise source. It is also helpful for the child’s orientation within a limited area and can be also used for developing rhythm skills.

For tactile stimulation, we use objects of different shapes, sizes, colours, textures, temperatures, as well as objects that vibrate, tactile books and even a professional “tactile wall.” The Little Room allows the child to enrich his/her sensory experiences by handling real objects – comparing characteristics of different objects and repeating different actions, as well as understanding the concept of space.”

## **New steps forward with Francophone Africa**

### **Larry Campbell, President, ICEV**

As most of you will know the French speaking countries of Africa are often overlooked in our development work because so many of us, myself included, lack the language capacity to be effectively engaged in those countries.

ICEVI’s Global Campaign on Education for All Children with Visual Impairment (EFA-VI) has been very concerned about this matter.

Therefore, it was a great pleasure in January of this year to welcome the Francophone Blind Union (FBU) as an International Partner Member of ICEVI.

This development has made a significant difference in raising the profile of EFA-VI within Francophone African countries. Not only does FBU now have a seat on the Executive Committee of ICEVI but they have become very actively engaged in promoting the program. Materials related to the Global Campaign have been translated into French and distributed to FBU members and they are helping ICEVI to get the program underway in Francophone Africa.

Francoise Madray-Lesigne, President of FBU and her colleague Andre Kowalsky from the Paris headquarters of FBU have already made two planning visits to Burkina Faso which has been selected as the first Francophone Africa country to become actively engaged in the EFA-VI program. Successful meetings have been undertaken with the Ministry of Education, UNICEF, the French and American Ambassadors and a number of international NGO's working with the country.

The Burkina Faso EFA-VI National Task Force will be convened in September with the support of the wife of President Campaore. ICEVI and FBU hope to have the program underway in early 2011 shortly after the scheduled national elections in November. Discussions with the government and non-government sectors have established a preliminary target of reaching 1,000 visually impaired children in the first three years of operation.

As I prepare this contribution for Dbi Review I have just returned from the quadrennial meeting of the Francophone Blind Union in Montreal where I had the opportunity to introduce EFA-VI Global Campaign to representatives of more than fourteen French speaking countries. Unfortunately, because of problems in securing Canadian visas, only about half of the delegates from the Africa region were able to participate.

However, there was a positive energy among the delegates who were in Montreal from Burkina Faso, Cameroon, Mauritius, Madagascar, Morocco, Mauritania, Senegal and Tunisia which I read as a good sign for the future of the EFA-VI program throughout Francophone Africa.

## **Networking in Brazil – where unity means strength!**

### **Introducing the 2011 Dbi World Conference hosts: Grupo Brasil and Adefav**

Stan Munroe reports that: Brazil was awarded the opportunity to host the 2011 World Conference of Deafblind International at the Dbi European Conference in Senigallia, Italy in September, 2009. As an opportunity to tell the Dbi community about the great progress being made in Brazil, the hosts were asked to provide a sketch of the deafblindness related programming throughout this vast country. The article is about networking in Brazil, and demonstrates how this process is so successful in Brazil.

GRUPO BRASIL (Group of Support to the Deafblind and Multiple Sensory Impaired)  
The national network Grupo Brasil works collaboratively towards change in the Brazilian perspective concerning the education and services for people who are deafblind and multiple sensory impaired. Grupo Brasil comprises the organizations: AHIMSA, the educational organization in São Paulo; ABRAPASCEM, the family



association and ABRASC, the organization representing individuals who are deafblind and many others, including government and non-government organizations.

### **Shirley Rodrigues Maia, the Chair of Grupo Brazil reports that:**

the education of people who are deafblind started in Brazil after Nice Saraiva Tonhozi took a course at the Perkins School for the Blind in 1967. Following her education at Perkins, Nice Saraiva Tonhozi set out on a journey to champion the education of people with deafblindness in Brazil. She created the first school in Brazil and in Latin America for this population, in the city of São Caetano do Sul, naming it the Anne Sullivan School.

From that milestone in 1967 through the 1970's there were periodical openings and closing of the school due to political problems during that time. The 1980's witnessed more stability with that program. Children with multiple disabilities were accepted to take part in their program. A parents group was formed at the School; for until then, parents did not get together to discuss their problems, support each other or look for their rights.

Furthermore there began an increase in services for people with deafblindness people in other parts of Brazil. In São Paulo in 1983, ADefAV, a Resource Center for multiple disabilities, deafblindness and visual impairment was formed. Then in 1991 Ahimsa was founded to expand upon the services in São Paulo first started by ADEFVAV.

Another positive development was the arrival of the Hilton Perkins Program (now Perkins International) working in Latin America to train and develop professionals to establish more services for people who are deafblind throughout the Region. Hilton Perkins also invested in an Association of Parents, offering a course to empower parents to become leaders. An important part of this development happened in 1995 when the IAEDB World Conference came to in Cordoba, Argentina, the first time the world conference was held in Latin America.

An important step for Brazil occurred in 1997 with the creation of the network Grupo Brasil to support the deafblind and multiple sensory impaired. With this network began the establishment of programs and action plans aimed at improving public policies for people with deafblindness and multiple impairments. This new network allowed for partnership work to be done at a distance with families, professionals and people with deafblindness.

Projects of this network included the creation of a data bank of people with deafblindness and multiple disabilities, the completion of a list of deafblindness related bibliography references and the development of a website.

Currently, Grupo Brasil promotes leisure and recreation activities with parents and people with congenital deafblindness; organizes fieldtrips and other interactions among people with acquired deafblindness – all in partnership with ABRAPASCEM and ABRASC, respectively.

Grupo Brasil has members in almost all Brazilian States. It organizes national regional, state and city Meetings; seminars; international meetings and forums for professionals, parents and people with deafblindness. Grupo Brasil has the goal to disseminate information, and for this, in addition to the website, publishes guidelines, leaflets and books on deafblindness and multiple sensory impairment.

The following is a listing of the main results from Grupo Brasil's actions:

- The Brazilian Ministry for Education acknowledges deafblindness as a unique disability.

- A number of major National Meetings and International Forums were held in recent years. These were organized with the support from such international organizations as Sense International – Latin America (UK), Perkins International (USA), CBM (Germany), Canada International Development Agency; and from such Brazilian governmental agencies as the National Secretary of Special Education, the National Secretary of Education (Ministry for Education), CORDE Coordinator of the Person with Disability (Ministry for Justice) and City and State Educational Secretaries from several regions of the country.
- The Brazilian Ministry of Work and Occupations have created the positions of Teacher for the Deafblind and Professional Guide-Interpreter.
- The Ministry for Education has created a sector to provide services to people who are deafblind with multiple impairments within the Center to Support the Deaf (CAS) and the Center to Support the Blind (CAP).
- There is now a city and state law declaring the ‘Day of the Person with Deafblindness’ in São Paulo, celebrated on the last Sunday each November. Actions are being taken to have this celebrated in more cities and states throughout Brazil.
- Deafblind International awarded Grupo Brasil the privilege to host the XV World Conference on Deafblindness. The conference will take place in São Paulo, Brazil, 27 September through October 01, 2011.

## **AHIMSA – Educational Association for Multiple Impairment**

### **Shirley Rodrigues Maia also reports that:**

Ahimsa was created on March 04, 1991 to provide educational services to people with deafblindness and multiple impairment. This educational facility supports a number of programs in the city of São Paulo as follows:

The program G.A.I. (Children Service Group) focuses on early intervention and preschool programs for children between 0 and 6 years old. The goal of the program is to fully develop the child’s social inclusion. The process involves ensuring that mothers or primary caregivers participate, together with the child and the teacher, to receive orientation on how to communicate, organize routines to develop opportunities for communication, orientation and mobility techniques geared towards improving the child’s autonomy and independence.

This program emphasizes expressive communication – how children express their emotions, thoughts and feelings and receptive communication – how the children receive information from the environment and from other people. The program places emphasis on developing consistent routines, which encourages the individual to anticipate facts, to understand what is going on around them and to motivate communication.

The program Functional I provides educational services for children between 7 and 10 years of age. In this program, the children already have a communication system established which allows them better social interaction in a group, and better able to explore all environments and contexts where they participate.

The program Functional II provides educational services for teenagers between 10 \_ and 14 years of age. In this program they start transition to adult life, with activities

more drawn to the community around the school; providing orientation to parents to seek vocational and professional activities in the community where they live. Within these two later programs there is the Fênix Project, which is aimed at children over 10 years of age who have never received any service before. With this project, the mother or primary caregiver must also participate to receive orientation and support.

In addition to these programs, Ahimsa also offers Pedagogic Support services to students enrolled in public schools and universities.

The Transition program is an Ahimsa partnership with Grupo Brasil, and is aimed at improving the quality of life and active participation in society for people between 16 and 26 years old by promoting their inclusion in the job market. Furthermore, Ahimsa and Grupo Brasil partner in a joint rehabilitation program for people with acquired deafblindness and those with acquired multiple impairments.

Ahimsa is also a Resource Center that offers a wide range of services, including: courses and training to teachers in public schools, either in person or through distance courses; videoconferencing and online classes; translation services; distribution of materials on deafblindness and multiple impairment through the Ahimsa website and distribution of CDs during the courses and lectures. Ahimsa supports the inclusion of people with deafblindness through partnerships with City and State Secretaries of Education and the Brazilian Ministry for Education.

## **ABRAPASCEM – Brazilian Association of Parents and Friends of the Deafblind and Multiple Sensory Impaired**

### **Márcia Maurílio Sousa and Susana Araújo report:**

that the mission of ABRAPASCEM is to organize, support and give guidance to parents and other family members of individuals with deafblindness in Brazil to improve their quality of life, through developing solidarity in an atmosphere of togetherness among the members.

ABRAPASCEM was founded by 20 families from different Brazilian states in 1999. Some of these families have stood for ‘the cause’ for more than 20 years at the schools and institutions where their children were enrolled.

Today there are about 350 families associated with the organization from all over Brazil. These families get together periodically to discuss issues related to the community where they live. They look for solutions through better public policies at their local governments to ensure the rights of those citizens who are deafblind and multiple impaired in areas of health, education, leisure and vocational services.

There are ABRAPASCEM groups in the states of São Paulo, Minas Gerais, Rio de Janeiro in the Southeast; in the states of Paraná, Rio Grande do Sul and Santa Catarina in the South; in the Northeast states of Bahia and Sergipe; in the Center-West states of Mato Grosso do Sul and the Federal State Brasília/DF and the states of Rondônia and Acre in the North.

ABRAPASCEM is a partner with Grupo Brasil in such projects as: ‘Project Adding Up’ – Leisure and Recreation and ‘Project Being’ – a Professional and Vocational workshop for people who are deafblind and their families.

During these past 20 years of activity, ABRAPASCEM has organized five National Meetings and several Regional meetings. Members of the Executive Board and

Financial Council have participated in International Meetings and projects with Family Associations throughout Latin America.

Members also take part in the Council of the Rights of the Persons with Disabilities at city and state levels. Currently, the various Regional members and the Board of Directors are heavily involved to ensure the inclusion in the school systems of children and young adults with deafblindness and multiple impairment. This activity is supported by Perkins International and the Lavelle Project.

## **ABRASC – Brazilian Association of the Deafblind**

### **Carlos Jorge Rodrigues and Claudia Sofia Pereira report:**

that the motivation for the founding of ABRASC, began following a meeting of people who were deafblind during the 4th Seminar of POSCAL, in Equador in 1998. Cláudia Sofia, who had been appointed as the leader from Brazil, together with other participants from meeting, decided to found ABRASC following their return.

At first it was very difficult to re-unite these people who met each other at that meeting, due to their lack of financial resources, and without any accompanying person or guide-interpreters available to travel together. After much search and mail exchange among those who knew how to read Braille, it was possible to find other people who were deafblind to become the first Board of ABRASC.

Now ABRASC has become legally registered in Brazil and is known widely in several parts of the country through the media, meetings and conferences. With the support of Grupo Brasil, three National Meetings of ABRASC have been organized involving the participation of people who are deafblind, their guide-interpreters, family members, professionals and others from their community.

ABRASC organizes courses to prepare guide-interpreters. Currently it has a project with the State Secretary of Education of São Paulo to prepare guide-interpreters to work at the public schools where young people with deafblindness are educated.

The goal of ABRASC is help improve the quality of life of all people with deafblindness in Brazil, by giving them the opportunity to develop personally, get together with their peers and, overall, to enable this population to participate in Brazilian society with the same rights and duties of any citizen of the country.

A major accomplishment of ABRASC happened in 2003 when the Yolanda de Rodriguez Day Center was opened in São Paulo to develop professional and vocational workshops. Other workshops are also available including cultural workshops, dance, capoeira (Brazilian type of martial arts), theater, art, and various sports and leisure activities such as adapted scuba diving, domino games and playing cards, etc.

The Bikeride for the Liberty of the Senses is an annual ABRASC event that takes place on the last Sunday of June of each year to celebrate Helen Keller International Week.

ABRASC motivates the members to continue standing for the recognition of deafblindness as a unique disability on a national level. Furthermore, it advocates for the recognition of Guide-Interpreters as a professional job category. Members increasingly take part in City and State Councils and are now seeking a Chair at

CONADE (National Council of the Disabled) to ensure that public policies are enforced and people who are deafblind are respected.

## **ADEFNAV**

### **Maria Aparecida Cormedi reports on another organization in Brazil called ADEFNAV, a Resource Center on multiple disabilities, deafblindness and visual impairment**

ADEFNAV was founded 27 years ago by parents of children with deafblindness, professionals and volunteers with the goal to provide service for these children. In the search for technical resources, ADEFNAV formalized, in 1991, their main international partnership with the Hilton Perkins Program (Latin America), Perkins School for the Blind, Watertown, Massachusetts, USA.

During the 1990's, in addition to children with deafblindness, Adefav started to provide services to children with multiple disabilities as well as for young adults and adults.

In 2000, Software AG, from Germany funded the construction of a building of 2000 m<sup>2</sup> (square meters), which was totally planned to meet the accessibility needs of the people with deafblindness and those with multiple disabilities.

Currently Adefav is a resource center for children, youth and adults (and their families) with multiple disabilities, deafblindness and visual Impairment.

The service objectives of Adefav are as follows:

- Encourage and support educational and social inclusion.
- Provide specialized educational services.
- Provide diagnostic services, referrals, assessment and intervention.
- Offer services of habilitation and rehabilitation.
- Provide staff professional development.
- Empower families and professionals.
- Disseminate knowledge in the areas of deafblindness and multiple disabilities.

Adefav's areas of service and intervention includes: diagnostic evaluation and functional assessment; early intervention; specialized educational services; transition to adult life; vocational guidance and daily life training for adults; therapeutic care; advocacy for educational and social inclusion; training courses; providing information to families (about laws, rights, policies and organization) and the dissemination of information about all the areas indicated.

It should be further pointed out that Adefav's influence and services are offered not only in São Paulo but in other states throughout Brazil.

Part of AdeFav's commitment to networking is that it works closely with other organizations mentioned previously to promote educational and social inclusion.

Furthermore, Adefav is networking closely with Grupo Brasil to host the the XV World Conference on Deafblindness which will take place in São Paulo, Brazil, 27 September through October 01, 2011.

## **Colombian communication ministry**

### **Supports its access for people who are deafblind**

In 2007, SURCOE the National Association of Deafblind people in Colombia, based on National and International laws for disabled people, such as access to information and communication, proposed a project called “CONNECTING SENSES WITH DEAFBLINDNESS” to the Colombian Information Technology and Communication Ministry. The proposal requested the creation of Information Technology (IT) rooms, paid for by the government, for people who are deafblind and people with multiple disabilities, to access the latest technology.

The way this works is that SURCOE selects a city where they know people with deafblindness live; they arrange a visit to present the plan to the authorities to set up the accessible IT room. They arrange for a meeting with government and non government organizations’ representatives. The organizations are invited to be part of the Project, encouraged to include this project as part of their own organizations’ action plans, as a way of guaranteeing their long term sustainability. From the participants attending these meetings, a local organizing committee is formed to guarantee availability of the following equipment and services:

- Accessible space and internet access for the people with disabilities
- Furniture and equipment (including insurance)
- A co-ordinator responsible for the service.

Once this is all in place, SURCOE signs an agreement with the organization(s) and offers training in deafblindness and IT to the coordinator, the users and the community leaders, who can themselves serve as future trainers to other people with disabilities in that city.

The next important step is to develop public awareness of the project. This is done with all the organizations that participated in the initial meeting, through arranging media events in the community and visits to the various institutions serving people with disabilities.

The final part is the monitoring and evaluation of the project to determine its impact after the first year of operation. During this period, SURCOE offers advisory support to the coordinator and the users as the need arises.

Through this project, SURCOE is ensuring that there is the funding for more people who are deafblind and isolated in different cities in the country, to access the technology, read a book, use the internet, hear music or chat with friends. As of May 2010, this program serves 1703 people with multiple disabilities including deafblindness in 12 cities throughout Colombia. There are plans to establish this service in four more cities during the second half of this year.

For contacts or information, please contact [sordociegoscolumbia@gmail.com](mailto:sordociegoscolumbia@gmail.com)

# Supporting the development of literacy in deafblind children

## through interactive dedicated software: a pilot project

Ben A.G. Elsendoorn<sup>1</sup>, Peter Brouwers<sup>2</sup> and Hans Luiken<sup>1,2</sup>

### Abstract

Aim of the project was to investigate whether the introduction of computer-controlled interactive activities and exercises could contribute to the development of literacy in a deafblind student with additional spasmodic motor problems. Special exercises were developed using dedicated software. Functional specifications were drawn up by the teachers who also supplied the linguistic content of the exercises. The types of exercises were conform to what was described in the child's personal development plan. All exercises were gradually introduced to the child who learned to work independently. In the end the exercises also turned out to be valuable additions to the curriculum of other deafblind children.

### Introduction

It is essential that the development of literacy in children with disabilities should be supported as much as possible by creating optimal circumstances in the classroom (Justice and Pullen, 2003). However, it has been noted that there is an unfortunate lack of research that aims at investigating how children with visual and multiple impairments, such as deafblindness, can best be supported (McKenzie, 2009). There still is a vast, uncultivated area of strategies that can be employed to support literacy development. This article will present an example of educational software and exercises which was designed for one specific deafblind child with spasmodic motor problems (who will be named M, hereafter), but which can also be used for other deafblind children without this additional constraint. The children are all students at the Royal Dutch Kentalis Rafael School for deafblind children. They vary in age between 5 and 18 years.

M is a nine-year-old, male child with very restricted visual capacities and limited residual hearing. In addition his motor skills are severely hampered by spasms, which prevent him from working with a computer using standard keyboard and mouse controls. M sits in a wheelchair which has a mounted restraint with a button that can be operated by the child's head to register his reactions in the computer system. Teachers expected that M's autonomy would increase as a result of the exercises: M would be able to select the exercise he wants to do and to autonomously finish a particular exercise. This could have a favourable effect on his well-being.

According to his teachers, the language development of this deafblind child with spasmodic limitations was judged to lag compared to his cognitive capacities. By means of extra exercises it was thought to be possible to increase his linguistic competence. However, adequate computer programs which would allow independent training were unavailable in Dutch. It was decided to develop a framework with a number of different types of exercises which could be filled with different linguistic content in order that they could be used repeatedly for different end-users with dissimilar levels of linguistic competence.

Educational pathways are established for all students at the school in their Personal Development Plans. The goals for M were the following:

- Controlled education to learn clicking by means of a one-button switch.
- Expanding his vocabulary.
- Recognition of words on the basis of their shape and contours.
- Development of his capacity to analyze and synthesize words with a maximum of three syllables.
- Stimulation of auditory processing of information.
- Understanding of a short story (presented auditory and visually).
- Relaxation through repetition and predictability.
- Coupling amounts to numbers.
- Managing educational exercises (puzzles and matching exercises).
- Developing a feeling of competence.

To this end various types of exercises were developed according to a specified framework, which could be filled with a diversity of linguistic content depending on the various targets accomplished at a certain point in time. Evidently the exercises that are presented have been previously selected by M's teacher to fit in with the Personal Development Plan. A variety of exercises have been developed and include action-reaction, matching, associating, sequences, reasons and results, relation between phonemes and graphemes, vocabulary, picture books and development of numeracy. Exercises were developed using the Classroom Suite authoring tool by Intellitools. Research showed that using Classroom Suites versatility provided significant improvement of reading performance for first grade students with disabilities or reading problems (Howell, Stanger, Erickson & Wheaton, 2000). Off-the-shelf software hardly ever does justice to a student's individual capacities, but with this system it is possible to develop exercises that focus on a student's competence in a specific modality. The authoring tool takes learning which is based on anchor stories as a starting point and can also be used in addition to an existing curriculum. Nearly all representations of language, such as written text, (synthetic) speech, sign language movies, and pictograms can be used in combination with video and images. By carefully noticing what the student needs the exercises can link up to his residual functions and his perception.

### **Functional specifications of the computer system and application**

Teachers of the school for deafblind children were asked to supply functional specifications for the application. Computer-control by M is carried out by means of a one-button switch, which he operates with his head. Since M cannot select from multiple options by a simple mouse click the possibility of making a choice has to be indicated in a different way. Exercises had to be developed in such a way that all possible choices were presented simultaneously on the screen. Each option could be activated in turn for a limited period of time. The active option is indicated by means of a blinking cursor underneath or, in the case of images, by highlighting the selectable picture. By pressing against the head switch, which then will function as the left mouse button, M can make his choice.

Because of his decreased visual capacities colour and contrast have been adapted for M; images, buttons can be enlarged and characters can be presented in different sizes against a contrastive background. M prefers character type Comic Sans in size 72 pts.



They are presented in black on a yellow background, as this is M's preferred contrast and colour combination. The program uses a 22-inch lcd full-colour monitor. Exercises are presented in a scanning mode, which means that all choices are simultaneously presented but remain clickable in turn for a certain period of time. This duration of this period can be determined by M and it allows him to select his own exercise. Because of his deficiencies M will have variations in processing durations. Being able to determine by himself the moment he makes a choice or gives an answer not only decreases the number of incorrect answers, but also gives him a feeling of autonomy. Of course a maximum time slot has been set in which M is considered to be able to give a reaction. By means of trial and error this time slot has been adjusted such that he is allowed to give a response without getting frustrated. At the end of each exercise, and sometimes even after each given response, M will be rewarded by means of a sound-supported, moving animation sequence. It is known that working with a computer can be very demanding for M due to his multiple sensory and motor impairment. The activities will therefore never exceed a thirty-minute duration. In addition, M's mood can be frequently subject to changes owing to his spasms. The degree in which spasms may occur are also influenced by external factors: loud sounds have a negative effect on M's well-being and may cause an increase in spasms. It is also known that his spasms will increase with age. M regularly needs help because of his uncontrolled movements. His computer configuration is such that he can work as independently as possible. The one-button switch has been mounted and fixed to his wheelchair such that it is not affected by M's spasmodic movements.

## **Developing activities and exercises**

M's personal development plan indicated that introducing new words or concepts could best be supported by images. These should represent objects that are familiar to him. (For another student it is obligatory to use her teacher's own voice, because she cannot handle other voices in an instruction situation).

Exercises have been put together in cooperation with and on the advice of various personal coaches. If necessary, the initial versions of these activities could be adapted in a second development round. Observing M doing these activities in the classroom and through conversations with his teacher we started to comprehend the effectiveness of the activity. In some cases this understanding resulted in either the activity getting adapted or in changing the way in which M was instructed in how to carry out the exercise.

To increase M's feeling of autonomy it was decided to present him with the possibility of selecting one of a number of different exercises. To facilitate his choice the exercises were printed on a sheet with stickers. M would choose one exercise, whereupon the teacher would remove the sticker from the sheet and stick it in M's personal calendar book. Next M would carry out the specific exercise on his computer.

It appeared that concentration played a very important role in changing or selecting an exercise. Therefore the teacher disabled the one-button switch during the instruction stage. This made it possible for the teacher to discuss the choice of the next exercise and for M to better focus on the conversation.

Repetition is of utmost importance to have knowledge rooted in students with such limitations. Hence in some activities, such as the picture book in which the story is read aloud, the student has the possibility to use the function "previous page". By

clicking this the same part can be listened to once more. When the student has autonomously listened to the picture book several times, the teacher may decide to disable this option.

## Results

Hitherto a total number of 85 different exercises have been developed for deafblind students at the Rafael School, of which 50 have been especially designed for M. A few of them will be described in more detail here. The simplest one is a detection and action-reaction activity: two images are presented and M can select either one of them. When he does, the selected word will be pronounced. At a later stage, two images were presented. The corresponding word of one of them would be read aloud and M would be requested to indicate which of the two was pronounced. At a more advanced level M would be shown pictures of people known to him and be asked to match the written name of one of them with the corresponding picture. At first these names would be pronounced, but at a later stage only the written name would be given. One of the picture books developed for M dealt with his holiday period with his grandparents. M would be able to go through this picture book at his own pace. Other exercises have been developed to train M's visual memory, e.g. when the task was to tell the hiding place of a particular object or to perform a memory task in a 3 x 2 field. For a few older students exercises were made with content in English. One particular task was to match the written denomination for a specific colour to the corresponding patch. In other tasks they were asked to match the written number to the corresponding symbol or carry out a memory game with numbers in English.

The main focus of the project described here has been on the development of a framework consisting of a range of exercises according to a particular outline or template. Linguistic content could be provided at various levels, depending on whom these exercises were intended for. For the students that have used these exercises in this experimental stage of the project no baseline has been established which would give a measure of their linguistic proficiency level at the start of the project. It has never been the scope of this project to investigate whether they would learn more quickly with these exercises than without them. What we did find beyond any doubt, is that the activities and exercises contributed positively to the expansion of their vocabulary and their linguistic proficiency, regardless of the fact that in most cases it still remained at a very basic level.

The activities definitely contributed to the feeling of autonomy with M. He reacted very enthusiastically to the fact that he was able to pick an exercise all by himself. His reaction was so vehement at times, that he would be seized by another spasm attack. Consequently, the teacher had to be present to help at the initial stages of a new exercise. It appeared that M could work increasingly autonomously when he became more acquainted with the (type of) exercise. M would give more and more verbal reactions because he was aware of the next step in the exercise.

At the start of the project it was decided that the Rafael teacher responsible for the school's information and communication technology would participate in the project. He was trained to work with the Classroom Suite authoring tool and would ultimately design his own exercises and exercise templates. It was hoped that by doing this, knowledge on how to work with the authoring tool would be secured in the school itself and knowledge could be transferred to other teachers at the school.

As the number of exercises and activities increased, so did the database with material consisting of images (photographs, pictograms, drawings), audio (spoken words,

sentences, texts and songs), video (movies and sign language movies), which were classified according to topics and themes. Teachers working with this database will ultimately adapt it to their own situation, which will make the database increase in size.

At present both the project and the software are being implemented in School Rafael. The system has been extensively presented to the school's teachers. They were given an overview of the programs possibilities. Workshops will be organized for them where they will be taught how to work with the authoring software so that they may start developing new exercises themselves. Since teachers have witnessed the results obtained with M, many of them now want to implement the software and the accessory exercises in their own educational practice. The choice to predominantly carry out this project in the school has resulted in a large acceptance with other teachers. For the moment, exercises and activities have been made available in the form of templates, which can be filled with linguistic materials by every teacher. As a result the project has turned out to be very flexible and employable for nearly all students.

---

<sup>1</sup> Royal Dutch Kentalis, PonTeM – Department for Research & Development, Sint-Michielsgestel, the Netherlands

<sup>2</sup> Royal Dutch Kentalis, Rafael School for Deafblind Children, Sint-Michielsgestel, the Netherlands

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## Conference

The 13th European Deafblind Week  
European Rehabilitation and Cultural Week of the Deafblind 2001  
in Tuusula, Finland  
Monday 1st to Sunday 7th August, 2011  
Hosted by the Finnish Deafblind Association

Dear Friends

The Finnish Deafblind Association confirms that the European Rehabilitation and Cultural Week of the Deafblind in 2011 will be held in Tuusula, Finland. The venue takes place in Onnela Inn and nearby Gustavelund Hotel and Conference Centre.

Tuusula is a small town with a rich cultural heritage. Both Onnela Inn and Gustavelund are situated next to beautiful Tuusula Lake, only half an hour from Helsinki and just 15 minutes from the airport.

The participation fee is 450 euros per person, including accommodation, full board and activities.

Further information about the programme for this week, registration and transport will be given in September 2010 the latest. Please, follow the Internet pages of the Finnish Deafblind Association at [www.kuurosokeat.fi/en](http://www.kuurosokeat.fi/en).

Finnish Deafblind Association was founded in 1971. Year 2011 will be our 40th anniversary. We are proud to welcome you to the European Rehabilitation and Cultural Week of the Deafblind 2011 as part of our 40th anniversary celebration.

For more information, please contact

Mr Heikki Majava  
Head of Organizational Affairs  
The Finnish Deafblind Association  
P.O.Box 40, Fi-00030 IIRIS  
Street address: Marjaniementie 74, Itäkeskus, Helsinki  
tel. +358 40 529 3439  
email: [ercw2011@kuurosokeat.fi](mailto:ercw2011@kuurosokeat.fi)  
[www.kuurosokeat.fi](http://www.kuurosokeat.fi)

## Between Silence, Shadows and Fragrances

**Creating new possibilities to improve the quality of life for people with deafblindness in the Dominican Republic**

Mr. Edgar Reyes, President of Asociación Dominicana de Sordociegos (ADSOC), shares an example of a way that deafblind adults can change their life when they can do something that they like while contributing to their families and community. In this

article he introduces a new initiative that ADSOC is promoting along with the reaction and feelings from a deafblind participant. Reyes invites us to read about this challenging and very exciting project.

## **Participating in the Market Place**

A micro-business managed by deafblind people in the Dominican Republic improves the awareness of deafblindness through marketing aroma products that they make and sell. María M. and Maurely E. are responsible for making and packaging these wonderful products.

Guided only by her hands, Maurely E. makes her way through boxes and containers that emit pleasant aromas. Accustomed to silence and shadows, this 19 year old young lady who is deafblind, was able to find what few people, like her, can. She found a way to participate in the market place!

Beside her, María M. from the Dominican Association for the Dead Blind (ADSOC), explains about her work as a workshop coordinator. Another ongoing responsibility of Maria's is her fight against the social and economic limitations that are imposed upon her as mother of a child who is deafblind.

In the Dominican Republic, as many as 3000 people are believed to be deafblind, according to Mr. Edgar Reyes, President for the ADSOC. The association works to identify people with this disability throughout the country in order to offer them support. Eight-eight adults who are deafblind form part of, and are supported by, this association.

Before the success of the micro-business project, the organization offered beauty and cleaning workshops to build an incentive for individuals to start their own personal business. In addition, it helped them with financial management, since this is a group that has great economic need.

## **Building success and self esteem**

María M. was a beneficiary of these classes. Today she divides her time between holding workshops for ADSOC and making personal products to sell in her neighborhood. She acknowledged that obtaining a job is not only difficult for the person with a disability but also for their family members. In her case, in addition to personal health issues, she is a mother of a boy who is deafblind. Consequently, opportunities for her finding a job were difficult.

Evelyn R. is one the 10 vendors who are deafblind who forms part of the group of distributors of the cleaning products. She testifies of the problems with mobility that she encounters due to her disability.

Before deciding to enroll in the school at 19 years of age, her social circle was limited to her parents and her house. Now that she is 35 she tries to work towards selling products to make a living. She has to do this by phone because she doesn't have a helper in order to sell door to door. Despite this, she has been successful in the four months that the project has been operating. "Besides being busy doing something, it is better to work to earn something rather than people giving you things. I feel more satisfied earning 10 pesos then receiving 200", she says.

Reyes notes that this change in attitude has to do with a change of focus in the traditional way of assisting the disabled. Having persons who are deafblind going out on the streets to sell their products not only allows them to develop socially through integrating in the community, but also changes their role in their family from being

passive to being active. In other words, they are no longer an economic burden for their families, which furthermore improves their level of self esteem.

## **Limitations and Dreams**

While the project's purpose is to increase the capacity to mobilize its members as workers in the work force, their success has being limited. To help boost their success, the organization offers classes in motivation and marketing; demonstrating how to establish commercial contacts with private and public businesses to sell their products. This all helps to accomplish self-sustainability, using the example of the micro-business, to generate more work opportunities for people with deafblindness in the Dominican Republic.

A factor further limiting the capacity of those with deafblindness in the Dominion Republic is the minimal availability of services for this population. There is a program for some children and young adults who attend Centro de Recursos para Discapitados Visuales "Olga Estrella" where they can learn academic concepts, Orientation and & Mobility and other skills to improve their readiness for some kind of work. However there are many people with deafblindness throughout the country who are not able to receive these services, remaining invisible and confined to limited spaces in their home.

Using the initiative of the micro business, ADSOC is looking towards a bigger dream: To create a Center for Deafblind People to assist those adults who never received any kind of services and have a lot of difficulties to live a normal life.

"This is what we are aiming for, however, this is something into the future", says Edgar Reyes.

Abridged from an article in Clave: Santo Domingo, Dominican Republic, September 17, 2009

## **Environmental Description for visually and dual sensory impaired people**

Environmental Description enables sensory impaired people to perceive spontaneous qualitative information in real time, through everyday life experiences. This type of received information can support a person's own actions and decision-making processes. Environmental Description provides focused sensations and experiences which encourage the visually impaired person to participate more fully and deeply in their environment.

This handbook analyses how we can describe the environment. It presents different methods and techniques which can be developed and applied to each individual user's perspective, ranging from life activities to artistic interpretations. It focuses both on the describer's and the receiver's perspectives; giving practical examples with additional exercises for professionals who work with visually and dual sensory impaired people. It includes ideas for getting started, and practical tips for the basis of various categories of descriptions. The book also includes comments and experiences of describing the environment in real-life situations from different individuals.

Environmental Description can be applied to the needs of a wide range of visually and dual sensory impaired people of various ages, their family members and friends. It provides a basic educational study book for professionals wishing to supplement their knowledge of how to apply different techniques including audio description for museums and art exhibitions.

Riitta Lahtinen MEd, PhD.  
Researcher, Teaching Consultant

Russ Palmer SRAT(M)  
Music Therapist,  
Visiting Lecturer

Merja Lahtinen MEd.  
Special Teacher of the visually impaired

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For further information contact:  
Email: rpalmer2@tiscali.co.uk

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## **See Me, Hear Me:**

### **A guide to using the UN Convention on the Rights of Person with Disabilities to promote the rights of children**

The first book to look at how two UN conventions can be used to support disabled children

Published March 2009 Price £9.95 ISBN 9781841871233

This publication can be ordered from our distributor, NBN International.

“an invaluable tool for practitioners committed to bringing an end to discrimination against children with disabilities” Yanghee Lee, Chair of Committee on the Rights of the Child

The UN Convention on the Rights of Persons with Disabilities represents the culmination of years of advocacy by the disability community in their struggle for recognition of their rights.

See Me, Hear Me is the first book to look at how this Convention can be used to support disabled children, alongside the UN Convention on the Rights of the Child. This guide’s analysis of the inter-relationship of the two Conventions, together with practical guidance on advocacy strategies and illustrations of good practice, make it an invaluable tool for child and disability rights advocates.

It is also an essential resource for governments in interpreting and implementing the two Conventions.

Author Gerison Lansdown is an international children’s rights consultant and has published and lectured widely on the subject of children’s rights, both nationally and internationally.

#### Related reading

- Disabled Children's Rights: A practical guide
- Including Disabled People in Everyday Life: A practical guide
- Getting it Right for Children: A practitioner's guide to child rights

programming

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## **Helen Keller International Award**

The 9th Helen Keller International Award will be launched at the Listen to Me 5 Conference for people who are deafblind and their families in Olomouc, Czech Republic July 27-August 01, 2010.

The competition is open to any artist and entries are invited that focus on exploring the senses and challenging perceptions of deafblindness. Works should consider the senses... touch, smell, sight, sound and taste.

Artworks in any medium are considered for selection and independent judges will choose which entries will be exhibited and have the chance of winning a cash prize.

All artists will remain anonymous until the judging is complete.

Further information and a full application pack will be available at the end of August on the Sense Scotland website [www.sensescotland.org.uk](http://www.sensescotland.org.uk), by email:

[arts@sensescotland.org.uk](mailto:arts@sensescotland.org.uk) or telephone: 0141 4290294.

The winner of the 8th Helen Keller International Award was Rick Curtis (USA). You can find more information of about the last award on [www.sensescotland.org.uk/news/8th-helen-keller-winner.php](http://www.sensescotland.org.uk/news/8th-helen-keller-winner.php).

## **Understanding visual and hearing impairment in Switzerland**

### **using the ICF classification system**

The Swiss National Association of, and for, the Blind (SNAB), is responsible for providing advice and support to people who are deafblind in Switzerland via its seven regional advice and support centres. The services provided by the centres include: social support, organising financial and human resources and giving training in techniques for coping with everyday life and lowering barriers. The techniques include visual and auditory measures and aids, computer use, communication techniques and mobility. In addition, SNAB organises adult education classes and group recreational activities adapted to the needs of people who are deafblind. The publication of the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization (WHO) gave rise to a discussion among the members of the SNAB team about the understanding of former and current disability models. None of the prevailing medical or social models seemed



entirely applicable, suggesting the resource-based models needed to be further strengthened.

New approaches within social work, including psychosocial counselling and the involvement of friends, family and colleagues, already focus in principle on the person's resources. Rehabilitation for the visually impaired in Switzerland, which places a strong emphasis from the start on the person's existing abilities, the development of new skills and the design of the person's surroundings, is clearly a resource-based approach. Despite this, our work is continually characterised by the consideration of deficiencies, illnesses and damage to visual and auditory systems. We are bound to this way of thinking, because we are generally faced with medical and, therefore, largely disease-based models of thinking. Examples of this way of thinking include: in discussions with the people affected and their relatives – "I have these problems with my eyes", "my ears are..."; in our cooperation and sometimes confrontations with social security and health insurance companies – "the visual acuity must be less than 0.2", "hearing loss of...", "...permanently needs outside help...", and in the expectations of the general public – "disability is an illness suffered by others" which forms the basis of charitable donations which represents 50% of our organisation's funding.

The seven SNAB advice centres for visually and hearing impaired and people with deafblindness have reinforced the focus on resources in their work. They are applying the International Classification of Functioning, Disability and Health (ICF), to visual and hearing impairment thus making it the starting point for a new SNAB tool.

## **What is ICF?**

The International Classification of Functioning, Disability and Health (ICF) is a classification system which describes people's functional health status, disability, social impairment and relevant environmental factors. This all-encompassing, modern system is structured around such broad components as body functions and structures, activities, participation and contextual factors. The resource-based, biopsychosocial approach of the ICF is an enhancement of the initial medical classification of disabilities developed by the WHO and the ICIDH (International Classification of Impairment, Disability and Handicap), which took as its basis the consequences of disease. ICF can be described as an impairment-and disability-based model. The complete description of the ICF classification system is available on the internet at [www.who.int/en](http://www.who.int/en) and [www.en.wikipedia.org](http://www.en.wikipedia.org).

Using the ICF to advise visually and hearing impaired people

The lists of human activities and participation in the ICF are particularly useful in relation to the work of an advice centre. These are as follows:

1. Learning and applying knowledge
2. General tasks and demands
3. Communication
4. Mobility
5. Self-care
6. Domestic life
7. Interpersonal interaction and relationships
8. Major life areas
9. Community, social and civic life

These criteria can be used to assess the living situation of people with a visual and hearing impairment. Catherine Woodtli (head of rehabilitation at the SNAB until spring 2010) and Helena Schuler (head of social work at the SNAB) asked the members of the teams from the seven SNAB advice centres to draw up a list of questions and topics relevant to the human activities defined in the ICF on the basis of their practical experience. These have been sorted out and used to create an ICF tool which will form the foundation for the advice and support given to visually and hearing impaired people. This new internal tool will be used to evaluate the clients' living situation, develop resources, broaden the focus of the work and structure the discussions during the advice sessions and interdisciplinary case meetings. It will help to ensure that topics and questions are not forgotten in the course of the day-to-day routine. This can be particularly important, for example, in the case of changes and upheaval in clients' lives (new school or job, moving house, new tasks at work, separation etc.). The systematic use of ICF categories will help the centres to provide advice which is based on clients' needs rather than on what the centres have to offer. An overall view of the living situation of the client should be the main focus of the advice, rather than producing quick solutions based on the services which the centre happens to be able to provide. The client's specific living requirements, but also his or her dreams and projects should be taken into account. On the other hand, the client's boundaries must be respected, in particular during intervention planning.

The ICF tool for acquired visual and hearing impairment has been developed on the SNAB's intranet, but the latest version can be printed out on easy-to-use A5 cards. The set of cards is called "ICF toolbox for acquired visual and hearing impairment". Each card relates to one ICF activity and/or participation and contains key words, topics and possible questions which, on the basis of our experience, could be important in the lives of visually and hearing impaired people of any age. The checklist will, of course, never be exhaustive. It is intended to act as a stimulus to take into consideration the many and varied aspects of the life of a person with a dual sensory impairment, even if the person in question and their environment do not place particular emphasis on these aspects. The cards provide help in structuring discussions, information about the aids currently available and other specific technical hints.

The work at the seven advice centres for visually and hearing impaired and people who are deafblind takes place in small interdisciplinary teams. As the teams begin to use the cards, they will add to them regularly. It will be easy to incorporate new information into the sets of cards and create added value. This is particularly important because, in contrast to the advice service for visually impaired people, there is no training for advisors for visually and hearing impaired people. Therefore, the process of developing, obtaining and passing on specific knowledge has to be organised internally. The cards are not confidential and SNAB clients can request a copy at any time.

We know of no existing advice and rehabilitation concepts based on the ICF and intended for acquired visual and hearing impairments and deafblindness either in Switzerland or elsewhere. By making use of the ICF and its forward-looking approach to disability, we hope to be able to shed more light on specific aspects of visual and hearing impairments and deafblindness and to provide the people affected with an advice service that meets their needs.

Stefan Spring, Catherine Woodtli and Helena Schuler,

SNAB Advice Centres for Visually and Hearing Impaired and Deafblind People  
Website: [www.szb.ch](http://www.szb.ch)

## Network News

Acquired Deafblindness Network

Co-ordinator: vacant

Website: [www.adbn.org](http://www.adbn.org)

Charge Network

Gail Deuce

Sense – Family, education and Advisory Service

The Anne Wall Centre

12 Hyde Close

Barnet, EN5 5JT

UK

Tel: +44 (0) 208 447 1133

Email: [gail.deuce@sense.org.uk](mailto:gail.deuce@sense.org.uk)

Communication Network

Ton Visser

Viataal

Theerestraat 42

Sint Michielsgestel NL - 5271 GD

THE NETHERLANDS

Tel: +31 - 73 - 55 88 111

Fax: +31 - 73 - 55 88 994

Email: [A.Visser@viataal.nl](mailto:A.Visser@viataal.nl)

Congenital Deafblindness in Adults Network

Dominique Spriet

QUENEHEM BP 53 Rue du Mont Saint Eloi

CALONNE RICOUART 62470

FRANCE

Tel: +33 - 3 - 21 61 16 16

Email: [sprietd@aftam.asso.fr](mailto:sprietd@aftam.asso.fr)

EDbN

Ricard Lopez

APSOCECAT & APASCIDE

C/Almeria, 31 ATIC

Barcelona ESP 08014

SPAIN

Tel: +34-678-712-619

Fax: +34-678-782-600

Email: [rlopez@sordoceguera.com](mailto:rlopez@sordoceguera.com)

Website: [www.edbn.org](http://www.edbn.org)

Employment Network

Seija Troyano

Nakskovinkatu 8 and 9

78200 Varkaus

FINLAND

Email: seija.troyano@dnainternet.net

Latin America Network

Sandra Polti

ARGENTINA

Email: Sandrapolti@yahoo.com.ar;

poltisan@ciudad.com.ar

Rubella Network

Nancy O'Donnell

Helen Keller National Center for

Deaf-Blind Youths and Adults

141 Middle Neck Road

Sands Point, NY 11050

USA

Tel: + 516-944-8900 x326

Fax: +516-944-7302

Email: nancy.odonnell@hknc.org

Siblings Network

Sabine Kersten

Koningsbeemdstraat 3

Lommel, B 3920

BELGIUM

Tel: +32 11 53 35 93

Fax: +32 11 53 35 93

Email: siblingsnetwork@gmx.net

Tactile Communication Working Group

Bernadette Van den Tillaart

15175 Prairie Road

South Solon OHIO 43153

USA

Tel: +1-740-426-6728

Fax: +1-740-426-6728

Email: bernadettevandentillaart@tiscalimail.nl

Usher Study Group

Marylin Kilsby

Sense

South East Regional Office

New Plan House

41 East Street, Epsom

Surrey KT17 1BL

UNITED KINGDOM

Tel: +44-845 127 0076

Fax: +44-845 127 0077

Email: usher@sense.org.uk

## **European Deafblind Network (EDbN)**

### **Ricard Lopez reports**

The European DeafBlind Network (EDbN) is beginning the publication of a periodical electronic bulletin called “Deafblind Europe”. Our aim is to strengthen links and promote experience and knowledge exchanges among all the European people, as well as getting the society closer to understanding deafblindness by publicizing the everyday work that all of us do.

That’s why we are asking for articles, news items, letters, notices of books, information of forthcoming events or whatever could be of interest. Photographs, drawings, charts or any other graphic material will also be welcome.

The involvement of all of us is the best way of creating a publication we all feel pleased about through valuable information and up-to-date news. We look forward to contributions from people who are deafblind, their families, professionals and volunteers.

Please send any contributions to:

Ricard López, EDbN

rlopez@sordoceguera.com

## **ADbN**

### **Acquired Deafblindness Network**

The Co-ordinating group of ADbN met in Aalborg Denmark on 20-21 March to finalise the programme for this years 8th Conference of ADbN “Building bridges – connecting people”.

Reflecting the continued growth in popularity of this event, the programme for the 2010 conference will include 7 plenary sessions instead of the usual 5. Also space for the 24 workshops was oversubscribed and so 4 additional workshops will be offered, reflecting the quality and variety of the subjects covered.

Registration for the conference is now open. At the last event in Bergen Norway we attracted over 200 delegates. We look forward to seeing old friends and new in Aalborg from 29th September 2010 – 3rd October 2010.

Check out the DbI website or go directly to [www.dbcent.dk/adbn2010](http://www.dbcent.dk/adbn2010).

Ges Roulstone

Former Chair ADBN

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

## **The Siblings Network**

### **Sabine Kersten reports:**

Raising awareness is still our main task. It is important to make sure that professionals, as well as parents, realise that growing up having a brother or sister who needs extra care, is different.

We will be present at the family conference Listen to Me5 in Olomouc, Czech Republic, which will be held July 27 – August 01, 2010. During this event there will be a separate programme of fun activities for brothers and sisters. This event always is a special meeting, where families meet and share experiences, feelings, worries and have fun.

For the period September 29th– 3rd October 2010, there will be a conference organised by the DbI Acquired Deafblindness Network (ADBN) in Aalborg, Denmark. We are planning to present a workshop about siblings to raise awareness of the different family situation in which brothers and sisters of children with extra needs grow up.

Furthermore we are working on better information about deafblindness and about being a sibling. Having access to age appropriate information is very important for children and teenagers. It will answer some questions and decrease worries they may have.

I hope to see some of you during Listen to Me or ADBN.

For information on the network or what we can do for your organisation, please contact:

Sabine Kersten at [siblingsnetwork@gmx.net](mailto:siblingsnetwork@gmx.net)

## **Usher Study Group**

### **Marylin Kilsby reports:**

The Usher Study Group has two main focuses – people with Usher and their friends and families and also professionals who work with, or who are interested in working with, people who have any Type of Usher syndrome. We are an international network which meets every two or three years, usually before or after a major conference.

This year, the Usher Study Group will be taking place on 27 and 28 September 2010 at the Hotel Hvide Hus, Aalborg, Denmark, prior to the ADBN conference. We have a rather ambitious programme which includes two sessions of workshops or special interest groups, when delegates will have to opportunity of networking and sharing their knowledge and experience. This, after all, is a Study Group, to which every delegate can contribute.

The USG would not be complete without Professors Bill Kimberling and Claes Möller, who will bring us up to date with the latest research into both the genetics of and possible future treatments for Usher syndrome. Several Usher people and Usher family members will be leading workshops, including an Ushers Only workshop and a Friends and Families workshop. Communication issues will be represented, as will a talk on young people with Usher. This group is growing ever larger as the Usher diagnosis takes place at a much earlier age than it did a few years ago.

Please contact me on [usher@sense.org.uk](mailto:usher@sense.org.uk) for a full programme and registration form. Closing date for new registrations is 31 July 2010.

We look forward to meeting you in Aalborg!

Marylin Kilsby  
Usher Projects Consultant  
Sense UK

## **New Usher Study Group Organiser Required**

I recently retired from Sense but am back at work on a short term contract until 31 October 2010, so that I can complete my work with the Usher Study Group among other projects. We will need a new organiser for the Usher Study Group, therefore, from 1 November 2010. This person will also represent the USG on the Board of Deafblind International.

If you are interested in finding out more about the role of USG Organiser, please contact me on [usher@sense.org.uk](mailto:usher@sense.org.uk).

Marylin Kilsby

Usher Projects Consultant, Sense UK

## **Rubella Network**

### **Trees van Nunen reports:**

Research on CRS continues in the Netherlands! Two organizations – Bartiméus and Kentalis (formerly known as Viataal) – work closely with patients who have combined vision and hearing loss. In 2004, my colleague Anneke Schoenmaker (MD) and I (psychologist) decided to collaborate together with our colleagues from Bartiméus (Josje Kingma, MD and Saskia Damen, psychologist) in a Health Watch Program that addressed both medical and behavioural late onset problems in the adults with CRS. Very few studies have looked at both aspects of the lives of these adults and we thought it might provide some interesting information.

As a first step, we collected medical and psychological data of approximately 65 adults with CRS born before 1985, most of them residential. Our initial reports received very positive reactions from our international colleagues. At the 2007 DBI conference in Perth, Australia, we presented a summary of the data collected and analyzed to determine the medical and psychological impact of congenital rubella syndrome in adults.

We subsequently developed a detailed classification system of psychological and behavioural problems found in this population along with a complete inventory of psychological and behavioural problems. I am happy to report that a student of our colleague, Marleen Janssen, is now analyzing the files of our CRS clients who are participating using the inventory I've designed. By studying the files (retrospective research) we hope that we can say something more about CRS as a late onset disease. The statistics will be run in late May. We are very curious about the outcomes and look forward to sharing them with you in the coming year. My goal is to present them during the DBI conference in Brazil in 2011!

### **Nancy O'Donnell reports:**

The Helen Keller National Center continues to collect blood samples of adults with CRS for the Centers for Disease Control and Prevention (CDC). The CDC hopes that they will be able to create a blood test that will definitively diagnose CRS in adults with a questionable or unknown diagnosis.

Our rubella listserv remains active and is an ongoing source of information and support for those with CRS, their families and professionals who work with them.

There is still so much to learn about late onset health problems associated with this syndrome. The latest topic on the list is whether a diagnosis of “CRS” entitles a person to certain services and/or financial support. There have been questions about mental health issues and CRS, and we have shared research articles that describe evidence that prenatal infections (including rubella) can contribute to increased risk for schizophrenia. Clearly, more research needs to be done.

Every week, I receive emails from literally all over the world with questions about CRS. We may hear from parents of a pre-school age child who want assistance finding resources for educating their child; a mother of a 2 year old who wants to know what kind of life her child might be able to live, or from a person in their 40s or 50s who is just now realizing that their health problems may be related to something their mother said about German measles many years ago.

This is the first generation of individuals with CRS being studied and followed. We are still learning a lot about this group and the long term effects of this virus. The Rubella Network is a great way to share information about this syndrome.

Nancy O'Donnell  
nancy.odonnell@hknc.org

## **Sensory Exploration Arts (SEA) program:**

### **EXPLORE, EXPRESS & ENJOY**

#### **creative expression through the arts**

“The arts motivate in a way that no other force can. It is only through making a mark that no one else could make, that we express the individual creative spark in our own humanity ,giving all individuals every opportunity to discover how wonderfully unique and special it is that they have known life and shared their feelings, responses and perception of living it.”

- Bernie Warren: Using the Creative Arts in Therapy and Healthcare.

The creative tides are high and the imaginative results continue to roll in with the launch of Sensory Exploration Arts (SEA) program.

DeafBlind Ontario Services, Canada is very pleased to share about the Ontario Trillium Foundation funded pilot project – Sensory Exploration Arts (SEA) program. This program is a joint venture with Bob Rumball Association for the Deaf (BRAD) in Milton, Ontario, Canada.

The initial concept of this project began after visiting SENSE Scotland in 2008 and observing the benefits and opportunities of the Arts and Wellbeing program. We wish to acknowledge and thank SENSE Scotland for sharing their insight into such an enriching and imaginative program and their continued guidance and support.

The objective of the Sensory Exploration Arts (SEA) program is to promote and foster artistic and creative expression in a visual arts program for individuals with sensory impairments. This project also includes the broader community through inclusion of local artists who work in various art mediums. The Sensory Exploration Arts (SEA) program is available to the residents of DeafBlind Ontario Services and the clients of Bob Rumball Association for the Deaf (BRAD). An additional objective of the



program is to select pieces of art to enter the International Helen Keller Awards, an open multi-media arts competition exploring perceptions of deafblindness from across the world, hosted by SENSE.

The pilot project involves two SEA coordinators, whose roles involve scheduling, developing and facilitating a visual arts program. The facilitation also entails being the conduit between the artist, various creative mediums, and the individuals who are deaf or deafblind and their Interpreter/Intervenors. The pilot project is overseen by a project manager and a steering committee.

This stimulating and collaborative program has already exposed the benefits of creative expression in individuals whom may not have engaged or viewed themselves as an artist before. Our vision for the SEA program is unfolding through the success of the following three fundamentals:

**Explore:** Experience exploration of life thorough the senses of smell, taste, touch, sound (vibrations) and sight (light/dark intensities) in context to the theme of the week providing individual emotional response, connectedness with the environment, sense of self and well being.

**Express:** Express the emotional response to the experience in the present moment in an art medium of (collage, painting, sculpture and printmaking) meant to validate ones humanity and wellbeing.

**Enjoy:** Creative self expression through the arts allows for further communication to others about how each person experiences the world in that moment. The arts validates their unique personality and abilities.

Our budding artists have explored and experienced many themes – animals, nature, sugarbush, and weather through watercolour, scented painting, warm/cool play dough, and barley, sand, beads, string and foil collages, all of which have allowed for play and exploration of their senses, deepening the participants joy of new experiences and life itself.

“Each person had their own perception of the experiences given and created a piece of art that reflected what they had experienced or how they wanted to express themselves in that moment. Everyone had the opportunity to create from their own imagination and make their ideas come to life through their art”, says SEA Coordinator and art therapist Corene Jonat, “Lots of smiling, laughing, quiet focus and excitement can be seen from the artists”.

The artists who are deaf and deafblind have expanded their comfort levels, communication and exploration abilities through these new experiences. We hope to secure more funding for this important project, and look forward to its continued success.

Kelly Patterson and Susan Manahan  
DeafBlind Ontario Services  
Canada

“I sometimes wonder if the hand is not more sensitive to the beauties of sculpture than the eye. I should think the wonderful rhythmical flow of lines and curves could be more subtly felt than seen. Be this as it may, I know that I can feel the heart-throbs of the ancient Greeks in their marble gods and goddesses”

– Helen Keller

## **John Tracy’s Inspiring Life**

**By Mary Claire Kendall, MD**

It is said – our strength is our weakness. In the case of Spencer Tracy and his son John Ten Broeck Tracy, who died in Acton, California – five days after the 40th anniversary of his father’s death on June 10, 1967 – nothing could be truer.

“Spence was considered by many to be the greatest actor the screen had ever seen,” his good friend, 80-year Paramount veteran, A.C. Lyles told me.

Yet, the painful emotion he felt upon learning, in 1925, that his baby son, John, was deaf was the hardest of blows. The only thing Spencer Tracy was not good at, he candidly admitted, was “life.”

His son John, on the other hand – dealt a whole series of setbacks, in what, at age 22, he would term “My Complicated Life” – was great at life.

If only Spencer Tracy could have read the script, he would have discovered John would soon hear the voice of God a little more loudly; see with the eyes of faith a little more clearly; and grow a big heart, drenched with hope and optimism.

As John’s daughter-in-law Cyndi Tracy said, “he just always had an uncanny ability to accept God’s love and always knew (his suffering) was going to be for a greater good.” It was never “Why me?” or “Poor me.”

God, he felt certain, had a plan.

### **The Plan’s Unfolding**

When Louise Treadwell met Spencer Tracy, her theatrical star was rising. Spencer, four years her junior, was just starting out.

It was early 1923. They were both arriving in Grand Rapids, Michigan to play in the same stock company. As fate would have it, they alighted the train station platform simultaneously.

The attraction between these two polar opposites, descended from, respectively, English blue bloods and working-class Irishmen, was immediate. Six weeks later, in between the matinee and evening shows in Cincinnati, Ohio, they got married. Nine months and two weeks hence, on June 26, 1924, in Spencer’s hometown of Milwaukee, their little bundle of joy arrived.

### **Turning Point**

One day, while John lay napping, the screen door accidentally slammed behind Louise and he kept peacefully slumbering on. She immediately, instinctively knew he was deaf. The diagnosis came back as nerve damage of unknown origin. Unbeknownst to

them, he had what's known as Usher Syndrome, which also causes gradual blindness due to Retinitis Pigmentosa – starting at birth.

The doctors said the Tracy's best option was to place John in an institution for retarded children at age six. The Tracy's would hear none of that and promptly went to work talking to him, reading him nursery rhymes, playing games with him... loving him.

"Spence," said Lyles, "was absolutely marvelous with him;" but "gave all credit to (Louise)" for John's progress.

Early on she "kept repeating the word 'talk'... a hundred... sometimes three hundred times" in twice or thrice daily "exercises." One day, said Lyles, when she finished, John, then 3 or 4, leaned his head close to hers and said, "talk" – his very first word. Tragedy again visited when John contracted polio at age six, leaving him with a withered right leg. That same year, Lyles recounted, Louise "gave up her career to devote herself entirely to her son and studied everything she could get her hands on about (educating deaf children)." No institution existed that worked with parents of deaf children, teaching them how to help their children develop a bridge to the speaking, hearing world.

Meanwhile, John's travails motivated Spencer to work that much harder so he could give his son all the financial help he needed to overcome his disability. Thus did he overcome what his good friend and fellow actor Lynne Overman said was a tendency toward laziness, thereby becoming the acting legend he was.

John learned how to lip-read perfectly, and was able to speak, read and write and was fully by age 11, when he began to write his daily journals. Three years later, he started "publishing" his "Newsy News" for friends and family.

When John was 17, Louise first spoke publicly, in her lovely English-accented tones, about raising and educating a deaf child. Her speech at the University of Southern California led her, a year later, in 1942, to found, in a campus bungalow, with Spencer's money, the John Tracy Clinic . It became the only such entity worldwide to provide gratis service to parents of infants and preschool children born with hearing losses.

Walt Disney, with whom the family played polo at the Will Rogers Ranch and The Riviera Polo Club, was one of the original board members.

In 1975, poignancy overflowing, Louise was the first recipient of the Father Flanagan Award for her special service to youth; and, around the same time, she helped establish the Boys Town National Research Hospital for Usher Syndrome : Boys Town, saved from bankruptcy and oblivion by Spencer Tracy's Oscar-winning performance as Father Flanagan, was now rescuing those who suffer John's same sensory afflictions.

### **"Our Everyday Blessing"**

John was always intent, as his son and fellow artist, Joseph Spencer Tracy, characterized it, on living "each day to the fullest, regardless" of his daily challenges. "I'm an artist, writer, photographer; I played polo, tennis; swim, water-ski, dance," he wrote in his journal in 1975. "I got married, had a family. I'm also profoundly deaf, going blind, had polio. What can you do?"

## **Well, apparently everything!**

Endowed with a high IQ and an athlete's body, he energetically poured himself into life, blissfully unaware of his multiple disabilities until he was in his twenties.

He loved horses, which mirrored his own "gentle" spirit, and the invigorating sense of freedom riding gave him: It reminded him of his "favorite" times of life at the family ranch in Encino (1936-1955), so full of fond memories like the day he started playing polo at age 12. (He had only begun riding three years earlier.) That day, one of the players was injured and Spencer summoned him to come on down!

Through it all, he had, said Cyndi, a "tremendous sense of humor" and the "charm of an angel." Fittingly, he did a dead-on impersonation of his father, which no professional comedian has ever attempted.

John graduated from Pasadena City College then attended Chouinard Art Institute, graduating in 1955, the same year his son was born. He subsequently worked at Walt Disney Studios in the props department for nearly five years, until his eyesight started failing. But, he continued doing his watercolor paintings and pen and ink and pencil drawings, as he was able to: He was declared legally blind in the early eighties and, by 1994, was totally blind.

"The moment you met him," said Cyndi, "your life was changed. You knew that you were in the company of someone... great, who was, at the same time, the most humble person you would ever meet." Quite simply, he had no idea how positively he impacted others' lives.

"Pa Pa Johnny," said Cyndi, "was truly 'our everyday blessing.'"

John attended Sunday services at All Saints Episcopal Church in Beverly Hills for decades with his mother, who died in 1983. He would also pray nightly in an elaborate ritual that, Cyndi said, revealed his "darling personality." The family – Joe's family, sister Susie, the cousins, among others – "was lined up in the (same) order every night." But "all his friends and acquaintances were always jockeying for position."

"He was strong until the end," said Joe, and "always prayed for other people, didn't pray for himself" – a lesson in selflessness he communicated to his three grandchildren.

As for actually communicating with words, John could talk, but his deafness combined with his blindness required some special techniques for his family to reply back.

Cyndi described how he loved to converse and remembered with particular warmth those special times, often at the end of a long day, she would be perched next to him as he would regale her with fascinating stories. And, she would reply by spelling words on his back. Or, for shorter responses, she would spell words on his hand – a hand that so often held her hand, while tapping her other hand, as he said, "God bless you, Cyndi. Thank you. "

For, whatever else he was, John Tracy was always profoundly grateful for all life's blessings.

## **<sup>1</sup>John Tracy Clinic**

**From Wikipedia, the free encyclopedia**

(right) The front of the Clinic and a preschool teacher walking children

John Tracy Clinic ([www.jct.org](http://www.jct.org)) is a private, non-profit education center for infants and preschool children with hearing loss in Los Angeles, California, USA. It was founded by Louise Treadwell Tracy, wife of actor Spencer Tracy, in 1942. It provides free, parent-centered services worldwide. The Clinic has over 60 years of expertise in the spoken language option. The Clinic offers worldwide family services, local family services, professional education, preschool, hearing testing, and more.

## **2 Boys Town National Research Hospital**

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

Since the opening of Boys Town National Research Hospital in 1977, the hospital has been internationally recognized as a leader in clinical and research programs focusing on childhood deafness, visual impairment and related communication disorders.

## **DbI Happenings**

### **Deafblind International is now a registered association!**

#### **Stan Munroe**

It might be surprising to many that DbI was never a legally registered organization. This is despite the fact that DbI rebranded itself with a new constitution and organizational structure thirteen years ago.

At a meeting in Madrid, Spain on July 18, 1997, the outgoing Executive Committee of the International Association of Educators of Deafblind Persons or IAEDB, its previous name, approved a new constitution guiding the activities of the newly named organization. Since that time, the constitution was amended several times to reflect required changes to the operation of the organization.

However, it was becoming so more clear to the Management Committee and Council that not being legally constituted was seriously limiting DbI's ability to campaign for funds and to receive international recognition, in particular with the United Nations. It was decided that, since the DbI Treasurer was employed by Viataal (now called Kintalis) in Sint-Michielsgestel, and that the finances of DbI were being managed by Viataal, it would be expedient to seek registration in the Netherlands.

After considerable discussion, the DbI Management Committee and Council approved the draft constitution prepared by the notary firm Huijbregts Notarissen, Sint-Michielsgestel, the Netherlands. Deafblind International became a legally registered organization on February 08, 2010.

How does the new constitution differ from the former one? Basically the new constitution bears very close resemblance, despite the Dutch legalese, to the former wording of DbI's constitution. DbI continues to be a membership driven association, with its objectives, organizational structure and operational procedures virtually unchanged from before.

Several name changes should be noted in the new constitution. The Council, which is responsible for managing the affairs of the organization, is now called the Board. The

General Assembly, which was the name of the former general meeting of the membership, is now simply referred to as the General Meeting.

Perhaps the most significant change with the new constitution is the provision for an annual General Meeting. Instead of a meeting of the entire membership or a General Meeting at the time of the World Conference (usually every four years), there is now an obligation for a General Meeting to be held each year.

At each annual General Meeting, DbI Management is to present to the Membership for approval, the state of affairs of the Association, the management conducted and the audited financial report. This change is recognized as a significant improvement in the accountability of management of DbI to its voting membership.

For a complete copy of the new DbI constitution, go to the DbI website [www.deafblindinternational.org](http://www.deafblindinternational.org)

## **It is up to you!**

### **Who will take the leadership for DbI in the period 2011 – 2015?**

#### **Who will become the next President and Vice-Presidents of DbI?**

Are you, or someone you know, interested to take on one of these officers roles? We are seeking dedicated and passionate persons who can take the lead in the further development of DbI, those who are willing and able to work in close collaboration with families, professionals and persons with deafblindness throughout the world.

#### **Who will have a seat on the council (board)\*?**

By serving on the Council (Board), Corporate members and Networks have a great opportunity to take DbI into the future, by taking on the responsibility of managing the association.

### **2010: Nominations year**

The DbI Nominations Committee urge you to have your say and take part in the process towards the election of the future President, Vice-Presidents and Council (Board) members of DbI, to be ratified during the General Assembly in the upcoming DbI International Conference in São Paulo , Brazil in 2011.

The first call for nominations should have reached all members by now. We hope you take the opportunity to make sure there will be a solid and dedicated leadership within DbI for the next four year cycle.

### **Guidelines for nominations**

When you consider nominations for President, Vice-Presidents and Council (Board) members, please have these guiding points from the Nominations Committee in mind:

1. The nominated person and corporate body must be a paid up member of DbI.
2. The nominated person must be willing to stand.
3. The nominated person should have the resources and capacity to attend meetings.

4. The nominated person must have the best interests of DbI at heart and approach the work in a positive and honest way.

### **Concerning the officers – President and Vice-Presidents:**

In addition to the above, the nominated persons must be able to meet the following criteria:

1. The nominated persons must be able to be unifying and demonstrate fairness and honesty.
2. The nominated person needs to be a good communicator and be able to represent DbI at the highest level.
3. A nominated Vice-President should be willing and able to deputise for the President, if necessary.

The Nominations Committee is seeking as wide representation as possible for the Council (Board). The Council (Board) will be composed of a President, two Vice-Presidents, the immediate Past-President, and no more than 35 other members, of which no more than 15 members will represent large corporates. This means that there will be up to 20 seats available for small corporates and networks. Council (Board) members will be appointed for a period of 4 years.

### **2011: Election year**

There will be held an electronic ballot to decide who will be President and Vice-Presidents. After the nominations process is terminated by the end of January 2011, all members who have the right to cast a vote will receive information on the voting process. This electronic ballot will be carried out from March to June 2011.

Note that DbI membership for 2011 must be paid by March 2011, in order for their vote to be accepted.

We hope you will take your time and consider thoroughly who you would like to see in these positions after the General Assembly during the upcoming DbI International Conference!

Any questions concerning nominations may be put to Knut Johansen [knut.johansen@signo.no](mailto:knut.johansen@signo.no), Norway – Chair of the Nominations Committee which has the following members:

Jackie Brennan, USA

Graciela Ferioli, Argentina

Celestine Hare, Australia

William Green, Italy (advisor and outgoing President)

\*Note: See article on new constitution which refers to what we once called DbI Council now as the Board.

### **Why Strategic planning is important**

For most of us, our central focus is people who are deafblind. We work hard to support, work alongside and communicate with them. We also strive to learn more

about the disability and to develop best practices to improve services to this population. Strategic planning on the other hand is boring, bureaucratic and a long way from what we really want to be doing!

Some of this is maybe true. However we can agree that we need frameworks to give context to our work; we need plans to work to and we want goals to strive for. A strategic plan will give order to our thinking, improve the paths of communication, help us to prioritise and guide how we allocate funds. A strategic plan should give a common understanding and help us to share the same vision.

The strategic plan is significant to all members of DbI and everyone can have a part to play in its development. Small and large corporates give expertise and funding; networks and individuals bring ideas and energy. The DbI Management Committee and Council try to make sense of all this and bring it all together.

Our current strategic plan covers 2009-2011. The DbI Council is aiming to review the current plan during its meeting in September 2010. This will allow the Council to have a new draft strategic plan (2012-2014) ready when the new officers and DbI Council are elected at the General Assembly in Brazil 2011. I'm sure the new Council will still want to put their 'stamp' on the strategic plan so that everyone agrees and understands the priorities for 2012 and beyond.

The current strategic plan states:

Our Vision

To be the international association which promotes services for deafblind people around the world.

Our Purpose

To bring together professionals, researchers, families, deafblind people and administrators to raise awareness of deafblindness. Central to our work is to support the development of services to enable a good quality of life for children who are deafblind and adults of all ages.

The 2009-2011 strategic plan has three main strands as follows:

1. Strive for an enhanced organizational capacity to meet the needs of people who are deafblind.
2. Influence the development of services for the benefit of people who are deafblind and their families around the world.
3. Strive to encourage improvements in practice and creation of new knowledge by facilitating improved communication and networking.

Many people have contributed to the large amount of work that has been done under each of these headings.

In very general terms the first theme covers the organisational strength of DbI so it refers to much of the secretariat work where systems and processes, website development have all improved. The capacity of the organisation also refers to our ever improving financial systems, the new constitution as well as membership and the nominations process.

The second theme refers to advocacy, awareness about deafblindness, influencing policy and working with partners. The final theme amongst other things includes DbI conference work, the information role and developing and supporting networks.

For our 2012-14 strategic plan we may not change our vision, purpose and these broad themes but we should consider priorities within them. Inevitably some of the work will be on going, for instance I'm sure a new strategic plan will still have conference



and network tasks high on our agenda. However do we want to consider new priorities? We could probably do more work around income generation and fundraising. More money is not an end in itself but it would obviously help us in the longer term to do more activities. Is research an area people want to prioritise or do we want to have a focus on education or the elderly?

There are many ways to get involved. You can write to me directly or to Elvira Edwards at the secretariat. You can speak to your corporate representative or get involved in a network. Every idea is helpful and I know there is plenty of energy and knowledge out there so share it with us so we can develop a strategic plan that isn't boring and bureaucratic but truly helps us in our work with people who are deafblind.

Gill Morbey  
Strategic planning co-ordinator

Contact [g morbey@sensescotland.org.uk](mailto:g morbey@sensescotland.org.uk) or Elvira Edwards  
[elvira.edwards@senses.asn.au](mailto:elvira.edwards@senses.asn.au) or check out the DbI website for a full copy of the DbI Strategic Plan, 2009-2011.

## **DbI Review is now available in Spanish**

DbI is pleased to report that the 44th edition of DbI Review is now available for Spanish readers, thanks to support from ONCE, the Spanish National Organisation of the Blind. The Spanish edition is available on the DbI website as follows:

[www.deafblindinternational.org/standard/publications.html](http://www.deafblindinternational.org/standard/publications.html).

This task was achieved by Pilar Gomez of ONCE for undertaking the translation; Eileen Boothroyd for editing and Geoff Dunn for graphic design.

A Spanish translation was something that DbI had achieved for some years in the past but this generous support from ONCE has now made it possible once again. It is a first step in satisfying a growing demand for DbI publications to be accessible in languages other than English.

With ONCE's continuous partnership, we should expect that the current edition and future ones will also be available in Spanish. This should further encourage membership in Spanish speaking countries and motivate professionals from ONCE and Latin America to write articles for the DbI Review that will be more widely available to the growing international community.

## **Report from the Vice-President Bernadette Kappen**

The past year has been a busy one for DbI. At the European Conference in Senigallia we completed the work needed to file for Association status. In February, we received the formal constitution and articles of incorporation for the Association. Receiving the document signifies the growth in DbI over its history. Starting as a small group of people in the late 1960s and then developing into a more official organization at the Canadian Conference in 1997 and now to have the status of an Association is very exciting. Through the direction of the Council, DbI has become more inclusive and focused on the work for the future. The current Strategic Plan offers a road map to our future success.

Becoming more professional is an important goal but our focus on the individuals who are deafblind and the staff who work with these individuals will always be the priority. DbI is known for its welcoming nature and for sharing information with colleagues around the world. This is truly unique as an organization grows and expands its reach. Our corporate members are growing and with this support we are able to accomplish many of the tasks in the Strategic Plan. I encourage you to discuss DbI and how it helps you in your work with other colleagues. It is important to our future that we continue to gain new members.

I hope you feel proud of your membership and that you are displaying your membership certificate in a prominent place in your agency. Please wear your DbI pin when you attend local events to encourage conversation about your work and DbI. I can only think about how positive our future looks. The World Conference in São Paulo in 2011 will be an opportunity for us to celebrate and have an update on the activities of DbI.

### **Introducing DbI's new information officer**

Stan Munroe, Canadian Deafblind Association (CDBA), has been serving on the DbI Council (now called the Board) since 1999 and the Management Committee since 2008. His connection with deafblindness began as a parent of a child born deafblind from congenital rubella syndrome. That situation led him and others to form the Canadian Deafblind and Rubella Association (now called the Canadian Deafblind Association), in 1975. Following a number of years volunteering with CDBA in various positions while having a previous career, Stan took contract employment with the organization in various capacities beginning in 1997, his latest one being (and now outgoing) as the Executive Director.

### **News from the Secretariat**

Over in Australia the Secretariat has been a hive of activity and we are pleased to report on our recent action.

### **Conferences and Meetings**

The Secretariat was pleased to support the Management Committee of DbI in preparation for the meetings held in São Paulo, Brazil in February 2010. The meetings were successful and a significant amount of work was accomplished.

Whilst in Brazil, we took to opportunity to meet with some members of the local planning committee for the 15th DbI World Conference. We toured the conference facilities and explored the wonderful city of São Paulo. The conference agency presented a professional and impressive plan and instilled absolute confidence in us that they are will execute an outstanding event in 2011. We would like to particularly thank Vula Ikonomidis and Shirley Maia for their exceptional hospitality during our stay. We were so warmly welcomed with genuine enthusiasm and we are looking forward to returning for the conference in 2011. The conference website is currently being developed and we will be pleased to circulate the link to members as soon as it goes live.

We attended the 8th National Deafblind Conference in Melbourne, April 2010. Small Corporate member Able Australia with the Australian Deafblind Council hosted an excellent conference with a thought provoking program and a fabulous mix of people in the field of deafblindness. The Secretariat was proud to promote DbI to the Australian community at the Conference. With William Green and Ges Roulstone in attendance as international keynote speakers, DbI was well represented.

The next meetings on the agenda are to be hosted immediately prior to the ADBN Conference in Aalborg, Denmark, September 2010. Preparations have already begun for the ManCom, Council & General Assembly meetings that will take place and we are very grateful to Else Marie Jensen from the Centre for Deaf for her assistance in planning these meetings.

### **Information Officer**

Following the ratification of CDBA as the provider of the new Information Function we have been pleased to be in close contact with new Information Officer Stan Munroe. Stan has taken to the role with much enthusiasm and vigour and we are pleased to be working together to improve the website functionality as well as keeping the content interesting and up to date. We encourage members to contact Stan with news on work and events you are involved in so we can share it with members and visitors to the DbI website. Stan can be contacted via email on [munroes@seaside.ns.ca](mailto:munroes@seaside.ns.ca).

A big thank you to Eileen Boothroyd for her unwavering commitment as the outgoing DbI Information Officer. It was a pleasure and a privilege to work with her.

### **Nominations Process**

Since Knut Johansen was elected as the Chair of the Nominations Committee at the Council meeting in Senigallia in 2009, we have been in regular contact to support him in developing the process for Nominations. Members now have the opportunity to nominate people for the position of DbI President, Vice-President(s) and members of Council. Nominations are due in by 31st January 2011 but can be submitted anytime now and will be ratified at the World Conference in Brazil 2011. We encourage members to seriously consider who they believe would be valuable in these positions as the people elected will be instrumental in shaping DbI and influential in making positive change for the future. For further information on the Nominations process, please contact Knut Johansen via email at [knut.johansen@signo.no](mailto:knut.johansen@signo.no).

### **Membership**

Membership renewal invitations were sent to all expired members earlier this year and the renewal response has been very positive. We are also pleased a number of new members have joined; both on an Individual and Corporate level and we look forward to being in regular contact with all members over the year. Likewise, we encourage members to keep in touch with us to inform us of your news and keep the DbI database accurate with up to date contact information.

If you haven't renewed your membership or know someone who would like to become a new member, please visit the DbI website to apply online:

[www.deafblindinternational.org/standard/membership.html](http://www.deafblindinternational.org/standard/membership.html).

If you would like an update on the status of your membership please contact the Secretariat on [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org) and we will be more than happy to assist with your enquiry.

We hope you enjoy receiving the emails from the Secretariat informing you of news and events of interest. If you haven't heard from us in a while, please send us a message so we can be sure to have your email address recorded correctly.

We look forward to continued correspondence with members for the remainder of this year and hope to meet up with many of you at the ADBN Conference in Denmark.

Thank you

Elvira Edwards & Bronte Pyett.

## Membership

### Deafblind International Individual Membership

I would like to join DbI as an individual member

I would like to renew my DbI individual membership

Member details                      Membership No.

Title    Surname                      First name

Organisation

Job Title

Address (Line 1)

Address (Line 2)

Town/City    State/County

Zip/Post Code                      Country

Telephone no. Fax no.

(Please include country and area codes)

E-mail address:

Are you:

a deafblind person     a family member     a professional

Does your organisation work primarily for/with:

blind people     deaf people     deafblind people

disabled people     other (please specify)

Your contact details will be made available to DbI members for DbI purposes but will not be made available for commercial purposes.

DbI Review (please check one box in each category)

I would prefer to receive DbI Review on:  paper     disk\*

(The disk version of DbI Review is supplied in text only format, on floppy disk)

Membership Fee please tick where appropriate

I wish to pay for 4 years' membership at the discounted rate of d100

### Corporate Membership

There are three tiers of Corporate Membership:

Large corporates Annual fees between d3,000 and d5,000

Small corporates Annual fees between d300 and d1,500

Mini corporates Annual fees between d100 and d250

Mini Corporate membership is available to interested organizations from the World Bank list of Heavily Indebted Poor Countries and Low Income Countries

We would like to join DbI as a Large / Small / Mini Corporate Member

Library membership fees d50 annually

(please delete as appropriate)

We submit an annual fee of d

Corporate members are entitled to receive 25/10/5 copies respectively of DbI Review.

We would like \_\_\_\_\_ copies

Member Details:

Organisation

Representative

Address (Line 1)

Address (Line 2)

Town/City State/County

Zip/Post Code Country

Tel: Fax

(please include country & area codes)

Email:

Website:

## How to pay?

In order to enable us to put your entire membership fee to use, we would kindly ask you to avoid sending us cheques as far as possible. By arranging your fee via bank transfer, we are able to keep banking charges to a minimum, thereby increasing the value of your membership fee. Naturally, for those of you who do not have access to this facility, we will be delighted to accept your fee by credit card, cheque or in cash.

Payment method  Bank Transfer  Credit Card  Cheque

A) Payment by Bank Transfer

If paying by bank transfer, please make payment to the following account:

Name of Bank: RABOBANK

Address of Bank: Sint-Michielsgestel, The Netherlands

Account Name: Instituut voor Doven: INZAKE DBI

Account Number: 11.29.09.825

Swift Address: RABONL2U

IBAN: NL31 RABO 0112 9098 25

Date of Bank Transfer:

Please quote the Swift Address and IBAN number in your instructions for Bank Transfer (If this is impossible and you have to send a cheque or international postal order then please contact us)

B) Payment by Credit Card

Card type:  VISA  American Express  Mastercard

Card no:

Expiry date Name on card:

C) Payment by cheque

Please make cheques payable to “Stichting Viataal Zorg inzake DbI” and post to: Ton Groot Zwaaftink – DbI Treasurer, Theerestraat 42, 5271 GD, Sint-Michielsgestel, The Netherlands. If paying by Eurocheque, please make out cheque in euros.

Please fax this whole page to (08) 9473 5499 or return to:

The Secretariat, Deafblind International, PO Box 143, Burswood WA 6100, Australia

## **Honorary Officers**

President

William Green

Lega del Filo D'Oro

Via Montecerno 1, Osimo 60027

ITALY

Tel: +39 - 71 - 72451

Fax: +39 - 071 - 717102

Email: [green.lfo@usa.net](mailto:green.lfo@usa.net)

Vice-President

Bernadette Kappen

The New York Institute for Special Education

999 Pelham Pkwy, Bronx, New York 10469

USA

Tel: (718) 519 – 7000

Email: [bkappen@nyise.org](mailto:bkappen@nyise.org)

Treasurer

Ton Groot Zwaaftink

Royal Dutch Kentalis

Theerestraat 42

Sint Michielsgestel Noord-Brabant 5271 GD

NETHERLANDS

Tel: +31 73 55 88 280

Email: [T.GrootZwaaftink@kentalis.nl](mailto:T.GrootZwaaftink@kentalis.nl)

Secretary

Elvira Edwards

Senses Foundation Inc.

PO Box 143

Burswood WA 6100

AUSTRALIA

Tel: +61 - 8 - 9473 5400

Fax: +61 - 8 - 9473 5499

Email: [Elvira.Edwards@senses.asn.au](mailto:Elvira.Edwards@senses.asn.au)

Information Officer

Stan Munroe

Canadian Deafblind Association

2652 Morien Highway

Port Morien, Nova Scotia B1B 1C6

## CANADA

Tel: +1 - 902 - 737 - 1453

Fax: +1 - 902 - 737 - 1114

Email: [munroes@seaside.ns.ca](mailto:munroes@seaside.ns.ca)

Strategy Group Leader

Gillian Morbey

Sense Scotland

43 Middlesex Street

Kinning Park Glasgow, Scotland G41 1EE

UK

Tel: +44 (0)141 429 0294

Fax: +44 (0)141 429 0295

Email: [gmorbey@sensescotland.org.uk](mailto:gmorbey@sensescotland.org.uk)

Networks Coordinator

Coordinator vacant

International Relations

Sergei Sorokin

Perkins International

175 N. Beacon Street

Watertown, MA 2472

USA

Tel: +1-617-924-3434

Fax: +1-617-923-8076

Email: [sergei.sorokin@Perkins.org](mailto:sergei.sorokin@Perkins.org)

## Large Corporate Members

### DENMARK

Interfond

Pierre J. Honore

Tel: +4563710218

Email: [pjh.interfond@mail.dk](mailto:pjh.interfond@mail.dk)

### FRANCE

French Deafblind Consortium

Jean-Marc Cluet

Tel: +33 - 1 - 4627 4810

Fax: +33 - 1- 4627 5931

Email: [a.n.p.s.a@wanadoo.fr](mailto:a.n.p.s.a@wanadoo.fr)

### GERMANY

CBM

Monika Brenes

Tel: +49 - 6251 - 131 320

Fax: +49 - 6251 - 131 165

Email: [Monika.Brenes@cbm.org](mailto:Monika.Brenes@cbm.org)

Website: [www.cbm.org](http://www.cbm.org)

German Deafblind Consortium

Wolfgang Angermann

Tel: +49 - 511 - 5100 815  
Fax: +49 - 511 - 5100 857  
Email: w.angermann@taubblindenwerk.de

ITALY

Lega del Filo d'Oro  
Rosanno Bartoli  
Tel: +39 - 071 - 724 51  
Fax: +39 - 071 - 717 102  
Email: info@legadelfilodoro.it  
Website: www.legadelfilodoro.it

NETHERLANDS

Royal Dutch Kentalis  
Ton Groot Zwaaftink  
Tel: +31 73 55 88 280  
Email: T.GrootZwaaftink@kentalis.nl  
Website: www.kentalis.nl

SPAIN

ONCE - Spanish National Organisation of the Blind  
Pilar Gomez  
Tel: +34 - 91 - 353 5637  
Fax: +34 - 91 - 350 7972  
Email: pgv@once.es  
Website: www.once.es

SWEDEN

Resurscenter Mo Gard  
Lena Hammarstedt  
Tel: +46 - 122 - 23600  
Fax: +46 - 122 - 23690  
Email: lena.hammarstedt@mogard.se  
Website: www.mogard.se

UNITED KINGDOM

Sense Scotland  
Gillian Morbey  
Tel: +44 (0)141 429 0294  
Fax: +44 (0)141 429 0295  
Email: gmorbey@sensescotland.org.uk  
Website: www.sensescotland.org.uk

Sense

Richard Brook  
Tel: +44 845 127 0060  
Fax: +44 845 127 0062  
Email: Richard.brook@sense.org.uk  
Website: www.sense.org.uk

USA

Perkins School for the Blind  
Barbara Mason  
Tel: +1 - 617 - 972 7502  
Fax: +1 - 617 - 972 7354  
Email: barbara.mason@perkins.org



Website: [www.perkins.org](http://www.perkins.org)

## **Networks**

Acquired Deafblindness Network  
Coordinator Vacant  
Charge Network  
Gail Deuce  
Sense – Family, education and Advisory Service  
The Anne Wall Centre  
12 Hyde Close  
Barnet EN5 5JT  
UK  
Tel: +44 (0) 208 447 1133  
Email: [gail.deuce@sense.org.uk](mailto:gail.deuce@sense.org.uk)  
Communication Network  
Ton Visser  
Viataal  
Theerestraat 42  
Sint Michielsgestel NL - 5271 GD  
THE NETHERLANDS  
Tel: +31 - 73 - 55 88 111  
Fax: +31 - 73 - 55 88 994  
Email: [A.Visser@kentalis.nl](mailto:A.Visser@kentalis.nl)

Congenital Deafblindness in Adults Network  
Dominique Spriet  
QUENEHEM BP 53 Rue du mont saint Eloi  
CALONNE RICOUART 62470  
FRANCE  
Tel: +33 - 3 - 21 61 16 16  
Email: [sprietd@aftam.asso.fr](mailto:sprietd@aftam.asso.fr)  
EDbN  
Ricard Lopez Manzano  
Joanot Martorell, street  
08014 Barcelona  
CATALONIA - SPAIN  
Tel: +34 93 331 73 66  
Fax: +34 93 331 42 20  
Email: [rlopez@sordoceguera.com](mailto:rlopez@sordoceguera.com)  
Website: [www.edbn.org](http://www.edbn.org)  
Employment Network  
Seija Troyano  
Nakskovinkatu 8 and 9  
78200 Varkaus  
FINLAND  
Email: [seija.troyano@dnainternet.net](mailto:seija.troyano@dnainternet.net)  
Latin America Network  
Sandra Polti

ARGENTINA

Email: [poltisan@ciudad.com.ar](mailto:poltisan@ciudad.com.ar)

Rubella Network

Nancy O'Donnell

Helen Keller National Center for Deaf-Blind Youths and Adults

141 Middle Neck Road

Sands Point, NY 11050

USA

Tel: + 516-944-8900 x326

Fax: +516-944-7302

Email: [nancy.odonnell@hknc.org](mailto:nancy.odonnell@hknc.org)

Siblings Network

Sabine Kersten

Koningsbeemdstraat 3

Lommel, B 3920

BELGIUM

Tel: +32 476 612 879

Email: [siblingsnetwork@gmx.net](mailto:siblingsnetwork@gmx.net)

Tactile Communication Working Group

Bernadette Van den Tillaart

15175 Prairie Road

South Solon OHIO 43153

USA

Tel: +1-740-426-6728

Fax: +1-740-426-6728

Email: [bernadette.vandentillaart@tiscalimail.nl](mailto:bernadette.vandentillaart@tiscalimail.nl)

[vandentillaart@tiscalimail.nl](mailto:vandentillaart@tiscalimail.nl)

Usher Study Group

Marylin Kilsby

Sense

South East Regional Office

New Plan House

41 East Street, Epsom

Surrey KT17 1BL

UNITED KINGDOM

Tel: +44-845 127 0076

Fax: +44-845 127 0077

Email: [usher@sense.org.uk](mailto:usher@sense.org.uk)

## **Mini corporate members**

NEPAL

Society of deafblind Parents, SDBP

Renu Lohani

Tel: 977-1 4600450

Fax: 977 1 4600450

Email: [rlohani@wlink.com.np](mailto:rlohani@wlink.com.np)

## **Small Corporate Members**

### **ARGENTINA**

Cooperative Association "Look with the Heart" (COOPA)

Beatriz Angelica Zoppi

Tel: +54 - 2302 - 430 690

Fax: +54 - 2302 - 434 274

Email: beazoppi@yahoo.com.ar

Perkins International - Latin America Office

Graciela Ferioli

Tel: +54 351 4234741

Fax: +54 351 4234741

Email: hperkins@fibertel.com.ar

### **AUSTRALIA**

Senses Foundation Inc

Debbie Karasinski

Tel: +61 - 8 - 9473 5400

Fax: +61 - 8 - 9473 5499

Email: dkarasinski@senses.asn.au

Website: www.senses.asn.au

Able Australia

Celestine Hare

Tel: +61 - 3 - 9882 7055

Fax: +61 - 3 - 9882 9210

Email: Celestine.hare@ableaustralia.org.au; info@ableaustralia.org.au

Australian Deafblind Council (ADBC)

Alisa Wills

Tel: +61 3 9882 8596

Fax: +61 3 9882 9210

Email: info@deafblind.org.au

Website: www.deafblind.org.au

The Royal Institute for Deaf and Blind Children

Alan Baynham

Tel: +61 - 2 - 9872 0366

Email: alan.baynham@ridbc.org.au

Website: www.ridbc.org.au

The Forsight Foundation for the Deaf/Blind

Trish Wetton

Tel: +612 9872 9000

Fax: +612 9872 9111

Email: foresight@bigpond.com

### **AUSTRIA**

Österreichs Hilfswerk für Taubblinde

Christa Heinemann

Tel: +43 - 1 - 6020 8120

Fax: +43 - 1 - 6020 81217

Email: c.heinemann@zentrale.oehtb.at

Website: www.oehtb.at

### **BRAZIL**

Grupo Brasil de Apoio ao Surdocego e ao Múltiplo Deficiente Sensorial

Shirley Maia-Rodriguez

Tel: +55 - 11 - 5579 5438  
Fax: +55 - 11 - 5579 0032  
Email: [grupobrasil@grupobrasil.org.br](mailto:grupobrasil@grupobrasil.org.br)  
Website: [www.grupobrasil.org.br](http://www.grupobrasil.org.br)

#### CANADA

Canadian Deafblind Association

Stan Munroe

Tel: +1 - 902 - 737 - 1453

Fax: +1 - 902 - 737 - 1114

Email: [cdbanational@seaside.ns.ca](mailto:cdbanational@seaside.ns.ca)

Website: [www.cdbanational.com](http://www.cdbanational.com)

DeafBlind Ontario Services

Roxanna Spruyt-Rocks

Tel: +1 - 905 - 853 - 2862

Fax: +1 - 905 - 853 - 3407

Email: [execdir@deafblindontario.com](mailto:execdir@deafblindontario.com)

Website: [www.deafblindontario.com](http://www.deafblindontario.com)

Resource Centre for Manitobans who are Deaf-Blind (RCMDB)

Jane Sayer

Tel: 1 204 284 6062

Fax: +1 - 204 - 477 - 1390

Email: [jsayer@rcmdb.net](mailto:jsayer@rcmdb.net)

Website: [www.rcmdb.mb.ca](http://www.rcmdb.mb.ca)

Rotary Cheshire Homes

Cindy Accardi

Tel: +1 - 416 - 730 - 9501

Fax: +1 - 416 - 730 - 1350

Email: [rchdirector@rogers.com](mailto:rchdirector@rogers.com)

Website: [www.rotarycheshirehomes.org](http://www.rotarycheshirehomes.org)

Canadian Deafblind Association (Ontario Chapter) Inc.

Cathy Proll

Tel: +1 - 519 - 759 - 0520

Fax: +1 - 519 - 759 - 1425

Email: [cproll@cdbaontario.com](mailto:cproll@cdbaontario.com)

Website: [www.cdbaontario.com](http://www.cdbaontario.com)

The Lions McInnes House - Group Home for Deafblind Persons

Joan Brintnell

Tel: +1 - 519 - 752 - 6450

Fax: +1 - 519 - 752 - 9049

Email: [LionsMcInnesHouse@rogers.com](mailto:LionsMcInnesHouse@rogers.com)

#### DENMARK

Center for Deaf

Else Marie Jensen

Tel: +45 44 39 12 50

Fax: +45 44 39 12 63

Email: [emj@cfidk](mailto:emj@cfidk)

Website: [www.cfidk](http://www.cfidk)

The Danish Resource Centre on Congenital Deafblindness (Videnscenter for  
Dovblindfodte)

Marianne Disch  
Tel: +45 – 41 - 93 24 65  
Fax: +45 - 99 - 14 73 44  
Email: [vcdbf@servicestyrelsen.dk](mailto:vcdbf@servicestyrelsen.dk)  
Website: [www.dovblindfodt.dk](http://www.dovblindfodt.dk)  
Centre for the Deafblind  
Lars Søbye  
Tel: +45 99 31 87 00  
Email: [laejs@rn.dk](mailto:laejs@rn.dk)  
Website: [www.dbc.rn.dk](http://www.dbc.rn.dk)  
Nordic Centre for Welfare and Social Issues  
Tel: +45 - 96 - 47 16 00  
Fax: +45 - 96 47 16 16  
Email: [nvcdk@nordicwelfare.org](mailto:nvcdk@nordicwelfare.org)  
Website: [www.nordicwelfare.org](http://www.nordicwelfare.org)  
Information Centre for Acquired Deafblindness

Ole Mortensen  
Tel: +45 4439 1175  
Fax: +45 4439 1179  
Email: [oem@dbcent.dk](mailto:oem@dbcent.dk)  
Website: [www.dbcent.dk](http://www.dbcent.dk)

#### FINLAND

The Finnish Deafblind Association  
Heikki Majava  
Tel: +358 40 778 0299  
Fax: +358 40 604 7477  
Email: [kuurosokeat@kuurosokeat.fi](mailto:kuurosokeat@kuurosokeat.fi); [heikki.majava@kuurosokeat.fi](mailto:heikki.majava@kuurosokeat.fi)  
Website: [www.kuurosokeat.fi](http://www.kuurosokeat.fi)

#### GERMANY

Graf zu Bentheim Schule-Blindeninstitut  
Eberhard Fuchs  
Tel: +49 9312 092 119  
Fax: +49 931 2092 1233  
Email: [eberhard.fuchs@blindeninstitut.de](mailto:eberhard.fuchs@blindeninstitut.de)  
Website: [www.blindeninstitut.de](http://www.blindeninstitut.de)

#### GREECE

Hellenic Association of Deafblind  
Diamanto-Toula Matsa  
Tel: 30-210-6440689  
Fax: 30-210-6440689  
Email: [diamatsa@gmail.com](mailto:diamatsa@gmail.com)

#### CHINA HONG KONG

Resource Centre for the Deafblind  
Hong Kong Society for the Blind  
Doreen Mui  
Tel: (852) 2778 8332  
Fax: (852) 2777 6559  
Email: [doreen.mui@hksb.org.hk](mailto:doreen.mui@hksb.org.hk)

#### ISRAEL

Nalaga'at Center

Adina Tal  
Tel: +972 3 633 08 08  
Fax: +972 3 682 37 15  
Email: [adina@nalagaat.org.il](mailto:adina@nalagaat.org.il)  
Website: [www.nalagaat.org.il](http://www.nalagaat.org.il)

#### ITALY

Danish Parents Association  
Lone Poggioni  
Tel: +39 075 51 79 413  
Email: [esbjerg@alice.it](mailto:esbjerg@alice.it)

#### NETHERLANDS

Bartimeus  
Marlies Raemaekers  
Tel: +31 - 343 - 526 650  
Fax: +31 - 343 - 526 798  
Email: [m.raemaekers@bartimeus.nl](mailto:m.raemaekers@bartimeus.nl)  
Website: [www.bartimeus.nl](http://www.bartimeus.nl)

Kalorama  
M. Verseveldt  
Tel: +31 24 684 77 77  
Fax: +31 24 684 77 88  
Email: [info@kalorama.nl](mailto:info@kalorama.nl); [M.Verseveldt@kalorama.nl](mailto:M.Verseveldt@kalorama.nl)  
Website: [www.kalorama.nl](http://www.kalorama.nl)

Visio  
Arthur Smit  
Tel: +31 - 55 - 5800 695  
Fax: +31 - 55 - 5800 890  
Email: [arthursmit@visio.org](mailto:arthursmit@visio.org)  
Website: [www.visioloof.nl](http://www.visioloof.nl)

#### NORWAY

AKS (Andebu Kompetanse- & Skolesenter)  
Anne Lise Høydahl  
Tel: +4733438600  
Email: [anne.lise.hoydahl@signo.no](mailto:anne.lise.hoydahl@signo.no)  
Website: [www.statped.no/aks](http://www.statped.no/aks)

Andebu Dovblindesenter  
Knut Johansen  
Tel: +47-33-438 700  
Fax: +47-33-438 720  
Email: [knut.johansen@signo.no](mailto:knut.johansen@signo.no)

Eikholt  
Roar Meland  
Tel: +47 3288 9050  
Fax: +47 3288 9052  
Email: [roar.meland@eikholt.no](mailto:roar.meland@eikholt.no)  
Website: [www.eikholt.no](http://www.eikholt.no)

Regional Resource Centre for Deafblind, Statped Vest  
Evabritt Andreassen  
Tel: +47-55-923 485  
Fax: +47-55-923491

Email: [evabritt.andreassen@statped.no](mailto:evabritt.andreassen@statped.no)

Skaadalen Resource Centre

Tonhild Strand Hauge

Tel: +4722703700

Fax: +47 - 22 703 715

Email: [tonhild.s.hauge@statped.no](mailto:tonhild.s.hauge@statped.no)

Website: [www.statped.no](http://www.statped.no)

RUSSIA

Rehabilit Centre for Deaf "Otofon"

Olga Smirnova

Tel: + 7495 4651 740

Fax: + 7495 456 0619

Email: [otofon@otofon.ru](mailto:otofon@otofon.ru)

Website: [www.otofon.ru](http://www.otofon.ru)

SINGAPORE

Lighthouse School

Koh Poh Kwang

Tel: +65-2503 755

Fax: +65-2505 348

Email: [kohpohkwang@lighthouse.edu.sg](mailto:kohpohkwang@lighthouse.edu.sg)

Website: [www.lighthouse.edu.sg](http://www.lighthouse.edu.sg)

SPAIN

APASCIDE - Spanish Association of Parents of Deafblind People

Dolores Romero Chacon

Tel: +34-91-733 5208

Fax: +34-91-733 4017

Email: [apascide@arrakis.es](mailto:apascide@arrakis.es)

Website: [www.apascide.org](http://www.apascide.org)

Spanish Federation of Deafblindness (FESOCE)

Ricard Lopez

Tel: +34 93 331 7366

Fax: +34 93 331 4220

Email: [fesocce@fesocce.org](mailto:fesocce@fesocce.org); [rlopez@sordoceguera.com](mailto:rlopez@sordoceguera.com)

Website: [www.fesocce.org](http://www.fesocce.org)

SWEDEN

FSDB

Helena Söderlund

Tel: +46-8-399 000

Fax: +46-8-659 5042

Email: [fsdb@fsdb.org](mailto:fsdb@fsdb.org)

Website: [www.fsdb.org](http://www.fsdb.org)

The Swedish Resource Centre for Matters Regarding Deafblindness

Lena Hammarstedt

Tel: +4687552368

Fax: +46 87552368

Email: [lena.hammarstedt@mogard.se](mailto:lena.hammarstedt@mogard.se)

Website: [www.nkcdb.se](http://www.nkcdb.se)

Specialpedagogiska skolmyndigheten

Anna Lena Steenson

Tel: +46-15852300  
Fax: +46-15852317  
Email: [anna-lena.stenson@spsm.se](mailto:anna-lena.stenson@spsm.se)  
Website: [www.spsm.se](http://www.spsm.se)

#### SWITZERLAND

SZB Beratungsstellen für hörschbehinderte und taubblinde Menschen

Stefan Spring

Tel: +41 62 888 28 66  
Fax: +41 62 888 28 60  
Email: [spring@szb.ch](mailto:spring@szb.ch)  
Website: [www.szb.ch](http://www.szb.ch)

Tanne, Schweizerische Stiftung für Taubblinde

Jette Ehrlich

Tel: +41 - 44 - 714 7100  
Fax: +41 - 44 - 714 7110  
Email: [henriette.ehrlich@tanne.ch](mailto:henriette.ehrlich@tanne.ch)  
Website: [www.tanne.ch](http://www.tanne.ch)

#### UNITED KINGDOM

Sense International

Amy Gray

Tel: +44 (0)20 7520 0980  
Fax: +44 (0)20 7520 0985  
Email: [amy.gray@senseinternational.org.uk](mailto:amy.gray@senseinternational.org.uk)  
Website: [www.senseinternational.org](http://www.senseinternational.org)

#### UNITED STATES OF AMERICA

The New York Institute for Special Education

Bernadette Kappen

Tel: (718) 519 – 7000  
Email: [bkappen@nyise.org](mailto:bkappen@nyise.org)  
Overbrook School for the Blind

Jackie Brennan

Tel: +1 - 215 - 877 0313  
Fax: +1 - 215 - 877 2466  
Email: [jackie@obs.org](mailto:jackie@obs.org)  
Website: [www.obs.org](http://www.obs.org)

#### VENEZUELA

SOCIEVEN, Sordociegos de Venezuela, Asociacion Civil

Maria Luz Neri de Troconis

Tel: +58 212 9911037  
Fax: +58 212 9911725  
Email: [socieven@socieven.org](mailto:socieven@socieven.org); [maluzneri@socieven.org](mailto:maluzneri@socieven.org)  
Website: [www.socieven.org](http://www.socieven.org)