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THE MAGAZINE  
OF DEAFBLIND  
INTERNATIONAL

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# Review



**Communication in the year 2000**

*See pages 4 - 13*



## A MESSAGE FROM THE PRESIDENT

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

*Dbl 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 the education of deafblind children and young adults. 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 *Dbl*.

*Dbl Review* is also available in Spanish. If you are interested in receiving the Spanish edition please contact:

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*Dear Friends,*

It is with anxiety that I write this first President's Message for *Dbl Review* ... anxiety first of all at filling the huge shoes left by my predecessor, Marjaana Suosalmi. She has most ably led Deafblind International into the new millennium by setting the organization on a course toward proper management and procedures.

Furthermore, my anxiety also stems from a natural concern that I will live up to everybody's expectations in this new role. Deafblind International is in a period of tremendous growth and expansion, and, as usual, successful work tends to breed even more work.

Nevertheless, I am also moved by excitement as I step toward this new task. So many new developments are



occurring in *Dbl*, and at a tremendously fast pace. We have just stepped away from a most successful World Conference in Lisbon. Our Portuguese friends and hosts at Casa Pia are again to be congratulated on their marvellous hospitality for this well attended conference.

We are witnessing this

## EDITORIAL

**I**t seems completely appropriate that at the time when we are about slip between one century and the next and from one millennium to another that *Dbl* is looking forward to the future and embracing change and planning for all it brings with it.

This Review, not surprisingly perhaps, focuses on the importance of communication between people and cultures and the ways in which lasting relationships can be fostered and maintained. Marianne Riggio is keeping her feet on the ground, while still reaching for the stars, as she looks back across the years

and records the field's many achievements and outlines the challenges still to come. We join the information super highway at high speed with Jim Belanich who provides an excellent introduction to the alternatives to "snail-mail" and urges us all to get involved. We meet the delightful Kaja, Per Lorentzen's daughter, and begin to understand, through her "chatter", a lot more about the nature of conversation.

Schools in South Africa and in Venezuela report their successes and aspirations and we have plenty of news of conferences, meetings, projects and people from

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year the first ever Asian Conference of Dbl, being held in February in Ahmedabad, India. We look forward to the next European Conference in the Netherlands in 2001. Our colleagues in Africa are talking about a first-ever African Conference, perhaps to be hosted in South Africa. And we are anticipating a very exciting World Conference in 2003, in Ontario, Canada, carried out with our Canadian friends' usual flair for organization and excellence. Furthermore, in our new Vice President, William Green, we have a man very dedicated to the fostering and proliferation of our Dbl networks, the very lifeblood of our organization. We also will soon have employed our first ever Administrator, a full time position to be shared with the

European Deafblind Network.

What a great era for our organization. Let us resolve to move forward in our daily work to advance the causes of deafblindness worldwide, and to contribute significantly to the field by our participation and contribution to all these activities.

**Michael Collins**

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countries all over the world. In this issue we have started a new feature highlighting individuals who are special to their colleagues and their countries and we hope to feature more in future editions. This time Canada and Eastern Europe are under the spotlight and a few people are going to be surprised when they open their copy of the magazine!

Dbl Networks are now firmly established within the constitution and from now on the Review will keep you up to date on all their workings. They will be reporting on a regular basis through our pages so new members can be recruited and everyone

kept in touch.

There is a lot to look forward to and I hope to hear from **you** – why not make a New Year's Resolution to get in touch and share your news with everyone!

**A Happy New Year!**  
**Eileen**



# Reaching for the stars with our feet on the ground

**Marianne Riggio – Hilton/Perkins Program**

With the arrival of each new year, many of us take time to look back and reflect on our accomplishments, our lives and to look forward to the future. Many of us will make a plan to realize our dreams – both personal and professional. At this time of year, the process of both looking back and looking ahead are somehow necessarily linked. As we turn our calendars to the new century, we are taking more of an extensive look at how far we've come and where we're going.

## Looking back over the century

When we think of the field of education, the special study and assistance to children and young adults who are deafblind and their families is really still quite new. Although we must always strive to help improve the opportunities for people who are deafblind to create a better life, we should also be proud of the strides that have been made by a committed body of families, professionals and the many important people who provide care and education for children and youth who are deafblind.

It is in the nature of most people who are in the human service professions to always try to improve the lives of others. Indeed, we must always maintain a healthy sense of dissatisfaction with the way that things are as we strive to help create a better life for those people who we serve. But, when we look today at the lives of people who are deafblind, we see how many possibilities can now be realized. The world of technology has made possible, what deafblind

people could once only dream about. Some people who are deafblind now can now easily converse with sighted-hearing people through the combined magic of the Internet world and adaptive computer technology. Children with severe physical disabilities now have a wide array of sophisticated devices to help them to unlock communication. The list goes on.

In the recent past we have seen new medical breakthroughs such as cochlear implants, eye surgeries, low vision and assistive listening devices that can now help people to have enhanced access to the world around them. As we enter this new millennium we are also fortunate that children who would once not have survived infancy are now able to share their lives with us. There are children and young adults with a wide array of abilities who have brought our field many new challenges, which we have come to accept and celebrate.

In the last quarter of this century, many countries have recognized that all children,

regardless of whether or not they have disabilities are entitled to go to school. Many countries have laws that mandate a full range of services to meet the unique needs of children who are deafblind. This has truly been a miraculous century!

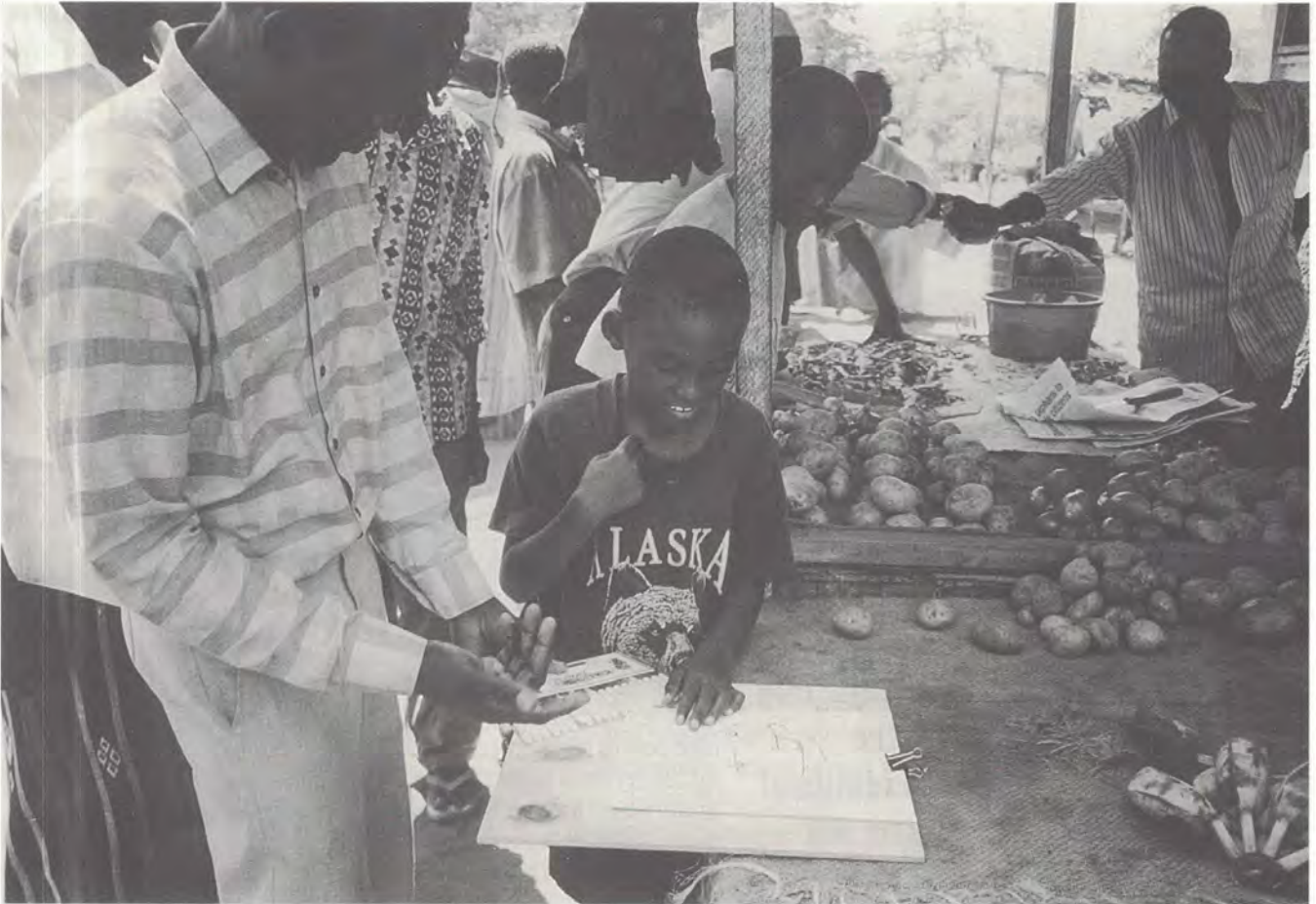
## The deafblind person in modern society

Many of us who live in modern societies often find ourselves a bit overwhelmed with life. We find ourselves with more things than we need (e.g., cell phones, sports utility vehicles, etc.). Many of us are caught up in a "more is better" world. Every day we find ourselves needing to do a little more and have a little more.

Likewise, I think in the educational world we have been a bit caught up in the same mentality. Often we feel that the solution to the educational challenges presented to us by a child is to prescribe a multitude of therapy and equipment.

Indeed, we are very fortunate that there is now a





wide array of support services and devices available to children with disabilities. These support services can make an enormous difference in the life of a child who is deafblind – that is if they are selected and used appropriately. For example, a communication specialist and physical therapist can work very effectively to help a child with physical disabilities utilize alternative communication systems that will make expressive communication possible. A low vision specialist can help the teacher select the most appropriate type of images to be used on a communication board. All of these are enhancers to the child's basic educational program. But we must be cautious to not make them the program itself.

## **Striking a balance**

Inevitably, we find, in conversations with friends and colleagues, the conversation is often drawn to the topic of wishing for a more simplified life. No, we don't want to give up our modern conveniences, but we want to slow the pace and improve the quality of our lives by simplifying how we live. We want to have time to invite our friends for a leisurely meal, to take a walk on the beach and search for seashells that we can make into a personal work of art.

As we think about the education of children and youth who are deafblind we must likewise try to create a balance by increasing the opportunities and possibilities, using support

**There are children and young adults with a wide array of abilities who have brought our field many new challenges, which we have come to accept and celebrate.**

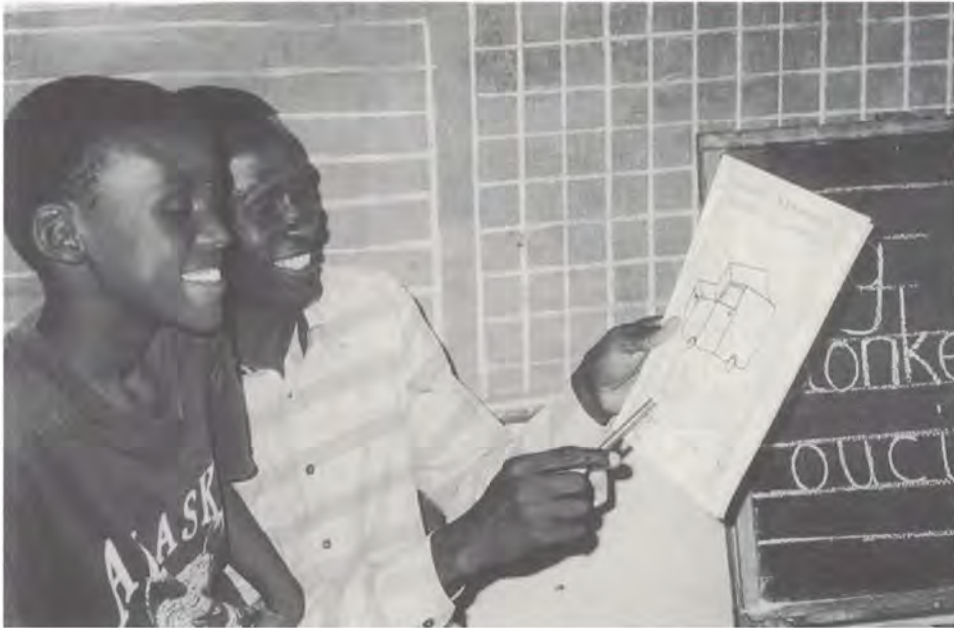
wisely, without compromising those elements that are truly important in helping them to build a happy and meaningful life.

If we can maintain this basic premise of equality, then thinking about how to create meaningful programs becomes easier. It is our job to help them to access every element of the world around them, and most importantly, help them to have the freedom to build lasting friendships and a happy and productive life.

## **Remembering the foundations of deafblind education**

It is our desire for, and the quality of our personal relationships that is the





foundation for our lives. As we develop services, we must not forget that it is our *personal relationships* with children and youth who are deafblind that must be the basis of any educational program. As our educational teams meet, we must analyze whether or not the program we are devising for a child will allow that child to develop meaningful relationships that are fundamental to a quality educational program.

It is the role of the educational team not only to develop a program that will foster relationships, but also foster the development of personal identity and self-esteem. We often use the term "whole child" when we talk of quality programs, but we must to reflect on what it really means to be a whole person. It is much more than learning how to talk, move, and take care of our own personal needs. Who we are is much more than that.

The word inclusion has become prominent in our educational system, and for many this term has different meanings. Our goal must be to fully include a child who is

**It is the role of the educational team not only to develop a program that will foster relationships, but also foster the development of personal identity and self-esteem.**

deafblind into the flow of life. We must include them by respecting their uniqueness, by taking time to help them understand the world around them, to help them create opportunities to share their gifts and contributions with others, to feel competent and to create a sense of pride in who they are.

Our goal as educators of children who are deafblind must be to foster a sense of personal well being and happiness in each of our school programs.

## **Creating the desire to communicate**

As we read the literature on deafblindness, we find that it focuses mostly on difficulties in communication. Truly, deafblindness is a disability of access and communication. We must remember, however, that the *desire* to communicate comes from the person's relationship with other people and a feeling that says: "I have something worthy to communicate". It is through our ability to communicate with another

person that we are linked to in a meaningful way.

## **Experiential Learning**

For all of us, our confidence in conversing about a topic comes from our own sense of security and understanding. It is therefore essential that we help our students to feel secure in their understanding of the world around us.

Jean Piaget, Jerome Bruner and other experts in child development have written extensively about the importance of early experiences in the development of cognitive concepts in children. For children who are sighted and hearing, many of these experiences happen in a very unplanned way. Many are learned by watching others and overhearing conversations. For children who are deafblind, these experiences do not occur without a very conscious effort of the teacher or caregiver. We must not only involve the child in the physical world, but we must converse with him about it in whatever way is understandable to him, and also let him engage us in conversations about those things that are interesting to him.

The breadth of what we communicate has to do with the quality of the experiences in our lives. Often, we do a good job as teachers by helping a child to anticipate events in their day, and to integrate the building of communication skills in the context of routine daily activities. Our challenge is to create a full range of opportunities that will truly liken their experiences to those of children who can see and hear.



## Are we helping the child who is deafblind to build an understanding of the world?

Helping a child who is deafblind to understand the world is the only way in which he can ever truly be a successful and confident individual. In our educational programs we must take the time to help him to fully and clearly understand the connectedness and meaning of the people and things that surround him. Just as the small infant first understands the local environment of his mother's arms, then gradually begins to explore more confidently. For the child with good sight and hearing learning important concepts and skills happens in a very casual way. For the child who is deafblind, however, we must carefully consider how to share these life experiences and help him to truly understand. This takes time, and yes, patience, but most importantly respect for the person who is deafblind. If a child who is deafblind gets fragmented and distorted information, he will never grow in competence as well as confidence in himself.

Many children and young adults who are deafblind have the ability to understand the mechanics of reading and writing, but we must offer them opportunities to cultivate their own interests and merge personal experience with literacy in order to assure true comprehension and meaningful self expression.

## Are we building a sense of community for people who are deafblind?

Community is defined as a "unified body of people with common interest" (Webster's Dictionary). In our attempt to

**Every day, we must incorporate into our teaching, ways for children to feel this sense of being an important part of a group, who share experiences and responsibilities.**



meet the very individualized needs of children and young adults who are deafblind, however, we often forget the importance of community. Although we think of community as being a geographic area with libraries and fire stations, community happens at many levels.

Friendship, perceiving ourselves as like other people, being a member of a family are critical aspects of all of our lives as members of a community. Every day, we must incorporate into our teaching, ways for children to feel this sense of being an important part of a group, who share experiences and responsibilities. We must also respect the rights of people who are deafblind to find their own community; to look for friends of their own and build a life of their own.

## Pride in One's Abilities

If we focus for a minute on the face of a young child who has just learned how to ride a bike, or tie his shoe, we can appreciate how important a personal sense of pride in one's abilities is in each of our lives. This pride comes from the way his accomplishments are regarded by the people around him. Organizations such as Special Olympics

have done an excellent job in providing opportunities for people with disabilities to feel a sense of pride in themselves. We must be sure however, that we are creating a spirit of success for the children that we serve.

Are we recognizing in our students their unique talents, and helping them feel a sense of honor in them?

## In closing

As we enter the new millennium with our students, it is especially important to look back and rely on those foundations of a strong program for children who are deafblind. It was Anne Sullivan's personal commitment to young Helen Keller that made her persevere in sharing with Helen every experience and conversing with her. That image should remain a model for us to hold on to. We must not however be fearful of the many possibilities for people who are deafblind. We must continue to create a new vision that will further widen and enrich their lives. Happy New Year.

**Remarkable Conversations – a guide to developing meaningful communication with children and adults who are deafblind** is edited by Barbara Miles and Marianne Riggio and is published by Perkins School for the Blind, 175 North Beacon St Watertown Mass. USA



# Creating new meaning – conversations with Kaja

Conversation takes many forms and in this article Per Lorentzen describes the possibilities for real communication with the help of his daughter Kaja and her teacher Liv Holmen.

I have discovered over the years, when trying to help parents and professionals in establishing communication with deafblind children, that it is not just talking to each other that matters. By that I mean the one-way sending and receiving of information. What matters more is being able to enter into a conversation with each other. When the deafblind child and his or her partner sensitively and responsively listen to each other, and each of them sensitively and responsively shape their language accordingly, then something very special happens. The deafblind person and the partner become co-authors of what is being said. They become co-speakers and co-listeners. They form a "we".

Such a co-authored conversation is not planned by either of them. What occurs in a conversation between a deafblind child and the partner, where they are truly intimate with each other, is genuinely creative. A unique response to currently shared circumstances emerges. What matters is the face-to-face responsive intimacy of the present situation. Such a face-to-face conversation doesn't just reshuffle old utterances and meaning, but creates new ones.

My starting point is that it is a primary human reality to be conversational. Conversation refers to all kinds of



**What occurs in a conversation between a deafblind child and the partner, where they are truly intimate with each other, is genuinely creative.**

communicative utterances and systems where two people mean something to each other and where this is shown in their interaction. It is not only about verbal conversations, but bodily and gestural ones as well.

So what does such a conversation look like when a deafblind child is involved? To answer the question, I will describe such an interaction between my own deafblind daughter Kaja and her teacher Liv Holmen. This is in my view a typical conversational situation involving these two people and it is a situation where they enter into discourse with each other. Even though they

do not use many tactile signs, this type of situation will lead to Kaja eventually acquiring more conventional signs.

Imagine Kaja is eating. She is sitting on her teacher's lap and on the table in front of them is a bottle with juice, a bowl of porridge, a moist cloth and a spoon. What are they talking about? What is the pattern of their utterances? Who is the most active in deciding the themes for conversation? How do they organize and handle the situation in order to create continuity and coherence?

The teacher fills the spoon with porridge from the bowl and lifts it in front of Kaja. This constitutes a typical way



of asking: "More food?" "Another spoonfull?" Kaja touches Liv's hand and pushes it away with an irritated grin. This is her answer: "No more food!" Liv puts away the spoon, stretches out her index finger and places it inside Kaja's hand. In this way they have initiated the starting position for Kaja's drink-sign, where she will either respond by pushing the teacher's hand towards her mouth or away. It is either "yes" to the bottle or "no". Kaja performs the "yes" gesture and their hands lose contact as Liv gets the bottle from the table. While she does this, Kaja places both her hands in front of her chest and awaits the bottle. When the bottle arrives, Kaja gathers her hands around it and brings it together with the teachers' to her mouth. She confirms the act.

With one hand she holds the bottle in her mouth while the other reaches out into the air and looks for Liv's hands. Liv catches her hand in hers and in this instant they are handling the problem of turntaking. Who is next to come up with a suggestion for a new theme? Liv notices that Kaja is looking up at a lightsource over the table and with an indicating gesture, she stretches both their hands out towards the ceiling: "Look! There's the light! We are looking at the light together!" Then their hands are moved into Kaja's lap. Another way of turntaking. Kaja now suggests they touch her bottle and she lifts the teachers hand to the bottle. Kaja places her hand at the end of the bottle and Liv confirms this by her own hand. She presses Kaja's hand lightly to the back of the bottle so as to indicate she is interested too. In addition she

makes Kaja feel the length of the bottle. This lasts for a few seconds. Then down into the lap again: "What now? Which theme? Your turn or my turn now?"

Liv stays passive and Kaja takes her hand and puts it on the edge of the table. Now the table is the theme. They feel it together, move their hands together sideways on the surface and remain in tactile contact. They feel the table and then Liv starts to knock the wood with Kaja's hand on top of her own in order to show her new aspects of this theme: "We can feel the table and we can knock on it!" Then follows a short pause where Kaja is drinking. She comes up with another suggestion: "Lets touch your face!" Kaja reaches for the teachers neck and pulls her head towards her own so that they hug. Kaja touches the teachers nose, mouth, ears, hair, necklace and Liv responds with her own actions reflecting her own perspective and state of mind. Every time Kaja touches Liv's nose, Liv bends forward and rubs her nose to Kaja's. When Kaja touches her mouth, she gets a kiss. When Kaja pulls her neck, she is hugged. After this hugging and face-touching, Kaja places her one hand out in the open air, it is grabbed by the teacher's hand and after a small hesitation they once again look up at the light in the ceiling. It is accompanied by a joint pointing gesture. Kaja takes the bottle out of her mouth and holds it in the air. Liv takes it and puts it in a make-believe way in her own mouth.

During the rest of their time, which lasts perhaps 15 minutes, they move between several themes: touching the table, exploring the bottle, hugging, touching the face, looking at the light, tickling



**Liv and Kaja "More food?"**

Kaja's thighs, drinking from the bottle alternately etc. Every time they touch upon a theme, Liv tries to add something new to Kaja's repertoire, making it a "theme with variations". All the time Kaja is drinking from her bottle and a few sporadic attempts to interest her in more food are firmly rejected. At one point in the situation when Kaja is drinking, Liv touches her front and her own front with Kaja's hand saying: "You and I are sitting here drinking!"

This very simple situation is similar in structure to a spoken conversation, although only a very few signs are used. The situation is similar to the daily "casual conversation" we have, i.e. a kind of chatting where there are no predetermined guidelines for what is being said and where both participants are free to suggest new topics, to say what they like and receive an immediate answer from the other. Such "chatting" is primordial. It's the kind of talking everybody knows and does first. Kaja and Liv must continuously handle the situation together and this

**This very simple situation is similar in structure to a spoken conversation**



## Creating new meaning – conversations with

Kaja

handling implies organizing the turntaking, placing their utterances, giving answers, suggest new themes, stating their opinions and showing each other their "inner" lives and state of mind in their "outer" actions.

The situation is one of cooperation so that the deafblind child can perform her communication and actions effortlessly. She is not lacking any capacity in this type of situation. There is immediate and direct connection between her own actions and utterances and those of her partner. She can "see" and "feel" these connections, and because of this she can internalise her own perspective and opinions about the wider world and understand the teacher's perspective too.

It is because of this "felt" connection she can learn most effectively from the teacher. In spite of the big differences in capacity between the teacher and the deafblind child, in this situation they speak the same "language" and they have a conversation where actions, utterances and emotions accompany each other. The situation is a joint endeavour. From such discursive actions, the sense of "I" and "You" emerges: "I am the person who utters and does this to you and you are the person who utters and does this to me. We are sharing, cooperating, creating together our situation and our ways of communication".

From here the way for more formal linguistic competence is wide open.

# The Internet and technology for people who are deafblind

## Jim Belanich from Helen Keller National Centre in U.S.A talks us through the benefits of the "Information Super Highway".

Historically, long-distance communication for people who are deafblind has been difficult. In most cases, people who are deafblind needed the assistance of sighted-hearing people, or were limited to direct face-to-face communication. With advancements in technology, this is no longer the case. People who are deafblind can now interact independently with friends, family, and colleagues around the world. The Internet is one medium that has provided individuals who are deafblind with a means to access the world.

### Equipment

Adaptive technology can help an individual who is deafblind to access the Internet. The equipment used for this access can take a variety of forms, depending on a person's visual and auditory ability. Individuals who are deafblind have varying degrees of vision and hearing, and as a result, there is no single method to access a computer that works for everyone. Each person must find the method which works best for themselves.

Technology is always in a state of flux. Advances in equipment and software are continuously moving the field forward. This is why it is important to be aware of new developments. The following is a brief description of some methods to access computers.

### Screen magnification

Information on a computer screen can be magnified by either installing a screen magnification program or by changing the settings for your computer. With screen magnification, everything that appears on a computer screen can be magnified. Of special note, when you magnify information on your computer, less information appears on the screen at any one time. Subsequently, you must manipulate the screen image to see everything available. One other important feature of screen magnification programs is the facility to modify the screen colours. By changing the colours, a person may make the screen easier for them to read. Computer screen magnification programs are more flexible than the magnification functions that come with your computer's operating system.

**Advances in equipment and software are continuously moving the field forward.**





**Keyboard with refreshable Braille**

### Braille displays

If a person who is deafblind is unable to read print, even with magnification, then Braille should be considered. It is recommended that when a person's visual prognosis is a progressive visual loss, Braille instruction should begin as early as possible. To access a computer, a form of Braille called "refreshable Braille" is used. With refreshable Braille, there is a strip of Braille characters. Each character space consists of either 6 or 8 pins that raise or drop to represent all possible Braille symbols. Refreshable Braille is used to access computers, as well as, text telephones (TTY), note-takers, and other communication devices.

With a refreshable Braille display, a user can access any information that is in text form. The one limitation of a Braille display is that it cannot show graphics. This can be a problem for some applications that rely heavily on graphics. Many icons, however, are now labelled with text so they can be accessed with a refreshable Braille display.

### Voice output

If a person who is deafblind has enough residual hearing to discriminate speech, a voice output system may be effective for them. A voice output system converts the text on the computer screen

to a spoken voice. The computer produces the speech by piecing together small bits of sound called phonemes. For example, in the English language there are 46 phonemes, or units of sound. The computer uses this combination of phonemes to produce the word. Because a computer is limited in how one phoneme blends into the next, the computer voice sounds robotic. For this reason, some individuals with mild hearing impairments who are still able to discriminate speech from another person may find it difficult to understand the computer's voice. Some people who are deafblind, therefore, use a

combination of speech with either Braille or magnification.

### Internet

The Internet is a computer network that links computers around the world. This network allows information on computers world-wide to be accessed from almost anywhere. The two most popular parts of the Internet are e-mail and the world wide web.

### E-mail

With e-mail, a text message is typed on one computer with access to the Internet and then sent to a storage site. The message is stored there until the intended receiver, the person to which the e-mail is addressed, logs onto the Internet and checks for e-mail. The primary advantage of e-mail over conventional mail is that e-mail can travel from one side of the world to the other side in a matter of seconds. From New York, I could send an e-mail to a person in Australia, and it could be waiting for them 30 seconds after I finish typing it.



**Adaptable print size can be achieved on screen**



E-mail is easily accessible because it is text. To send an e-mail, you need to know the e-mail address for the person you want to contact. An advantage of sending e-mail as opposed to a traditional paper and pen based letter, is that the receiver of the e-mail can read it in their preferred mode. A person who uses a Braille display to access their computer can read their e-mail in Braille, regardless of how the sender wrote the e-mail. So with e-mail, a sender does not need to write in Braille to a Braille reader; this opens the door for increased communication options.

One specialized form of e-mail, is called a listserv. With a listserv, people send e-mail to an address, which in turn sends out that e-mail to all subscribers of the listserv. For example, there is a listserv called "deafblind" which has subscribers who are deafblind, family members of people who are deafblind, and professionals in the field of deafblindness. This listserv has subscribers from around the world. A person posts an e-mail on the listserv, which is then sent to all subscribers. This allows every subscriber to learn about deafblindness from all over the world.

A few examples of listservs regarding deafblindness can be found in the box.

## Listserve concerning deafblindness

### *Charge Syndrome Mailing List*

The topic of this listserv is Charge syndrome.

To subscribe to this list, send the following in the body of an e-mail message (leave the subject line blank) to

<[majordomo@avenza.com](mailto:majordomo@avenza.com)>:

Subscribe CHARGE-L for your email address.

### *Deaf-Blind Mailing List*

This is a general deafblindness listserv. The purpose of this list is to share information, inquiries, ideas and opinions on matters pertaining to Deaf-Blindness. Professionals, persons who are deaf-blind, and their families and friends are subscribers to this listserv.

To subscribe, send the following command: (leave subject line blank if possible) to:

<[listserv@tr.wou.edu](mailto:listserv@tr.wou.edu)> :

Subscribe DEAFBLND <firstname lastname>

### *Retinitis Pigmentosa Mailing List*

The topic of this list is Retinitis Pigmentosa.

To subscribe to this list, send the following in the subject of an e-mail message to

<[listserv@maelstrom.stjohns.edu](mailto:listserv@maelstrom.stjohns.edu)>:

Subscribe rplist (your first and last name)

### *Usher Syndrome Mailing List*

The topic of this list is Usher Syndrome.

To subscribe to this list, send the following in the body of an e-mail message (leave the subject line blank) to:

<[majordomo@farside.cc.misu.nodak.edu](mailto:majordomo@farside.cc.misu.nodak.edu)> :

Subscribe USHER-LIST your email address

## World Wide Web

The world wide web consists of millions of web sites, each web site containing information and hyperlinks to other web sites. These hyperlinks allow a user to seamlessly jump from one site to a linked site. For example, if a user is reading the HKNC web site (which is stored in New York) and presses the hyperlink for DBLink, the user will jump to their web site which is in Oregon – 3,000 miles away – in seconds. From there the user can jump to the Sense web site in London, and then just keep going. This allows users to access vast amounts of information quickly.

Many goods and services are available through the world wide web. It is the fastest growing market place today. Through the web, people who are deafblind can access news, the weather, and endless other forms of information. Many others do their shopping on-line. Just about anything can be bought over the web, including: clothes, food, computers, furniture, and airline tickets. With the Internet, a person who has difficulty getting out to the store, can now visit the store's web site, browse through a description of the merchandise, and purchase what they want with their credit card. The items are then delivered by mail. This can be done completely independently.

## Distance Learning

A growing trend in education is distance learning. There are now several colleges and universities that are offering classes over the web. Instead of going to a classroom and needing a sign language interpreter and a note-taker, a student who is deafblind taking a class on the web will



receive text lectures and can send their assignments back as e-mail. The information available in this type of class is more accessible than a typical class, because the person who is deafblind accesses the information in their preferred mode: Braille, magnified print, or voice.

## Personal Communication

The web also provides people who are deafblind with a means for personal communication. There are two web applications that allow people who are deafblind to easily communicate with other people: chat rooms and instant messaging.

A chat room is place on the Internet where people log-on at the same time. Then anyone who is logged-on to the same chat room can type messages which are simultaneously viewed by all others who are logged-on to that chat room.

With instant messaging, the user types a brief note to someone who is simultaneously on-line. They receive the message and type back. This back and forth typing of messages is similar to having a text telephone (TTY) conversation. Three widely used instant messaging services are America On-line, www.ICQ.com, and the MicroSoft Network (www.MSN.com).

## In conclusion

Technology has opened countless doors for individuals who are deafblind, and hopefully in the future doors will continue to swing open. The Internet has a lot to offer individuals who are deafblind. It can help decrease a feeling of isolation by overcoming communication barriers.

## Web sites to learn more about deafblindness

### American Foundation for the Blind

15 West 16th Street  
New York, NY 10011  
(212) 626-2000  
[www.afb.org](http://www.afb.org)

### APASCIDE – Asociación Española de Padres de Sordociegos (Association of Parents of Deafblind of Spain)

[www.arrakis.es/~apascide](http://www.arrakis.es/~apascide)

### Australian DeafBlind Council

PO Box 267  
Clifton Hill Victoria  
Australia 3068  
Telephone:  
Voice (03) 9482 1155  
(+61 39 482 1155)  
TTY (03) 9489 3091  
(+61 39 489 3091)  
Email: [dba@internex.net.au](mailto:dba@internex.net.au)  
<http://home.internex.net.au/~dba/>

### Canadian National Institute for the Blind

1929 Bayview Avenue,  
Toronto, Ontario M4G 3E8  
Tel: 416-480-7415 | TTY: 416-480-7417  
[www.cnib.org](http://www.cnib.org)

### Center for Deaf-Blind Persons

Beth David Institute  
13 Yad Lebanim Ave.  
PO Box 9259  
61 092 Tel Aviv, ISRAEL  
[http://www.weizmann.ac.il/~xlacha1/deaf-l\\_faq/il-deafblind.html](http://www.weizmann.ac.il/~xlacha1/deaf-l_faq/il-deafblind.html)

### DB-Link: Information Clearinghouse

Teaching Research  
Division of Western  
Oregon State College  
345 North Monmouth Ave  
Monmouth, OR 97361, USA  
(503) 838-8776  
[www.tr.wosc.osshe.edu/dblink/index2](http://www.tr.wosc.osshe.edu/dblink/index2)

### DeafBlind New Zealand – National Office

Box 109-583  
Newmarket  
Auckland, New Zealand  
Tel: 64 09 625 8575  
[tfree@rnzfb.org.nz](mailto:tfree@rnzfb.org.nz)  
[www.deafblind.org.nz](http://www.deafblind.org.nz)

### Föreningen Sveriges Dövblinda (FSDB) (Association of the Swedish Deafblind)

S-122 88 ENSKEDE,  
Sweden  
Tel. +46 8 39 90 00  
E-mail: [fsdb@fsdb.org](mailto:fsdb@fsdb.org)  
[www.frukt.org/fsdb/eng-info.html](http://www.frukt.org/fsdb/eng-info.html)

### Gallagher, James

E-mail: [James@deafblind.co.uk](mailto:James@deafblind.co.uk)  
A-Z to Deafblindness web site  
[www.deafblind.com/index](http://www.deafblind.com/index)  
[www.deafblind.co.uk](http://www.deafblind.co.uk)

### Helen Keller National Center

111 Middle Neck Road  
Sands Point, NY 11050, USA  
(516) 944-8900  
[www.helenkeller.org/national](http://www.helenkeller.org/national)

### Hilton/Perkins Program Perkins School for the Blind

175 North Beacon St.  
Watertown, MA 02472 USA  
Tel: 617.972.7228  
Fax: 617.923.8076  
[www.perkins.pvt.k12.ma.us/hiltperk.htm](http://www.perkins.pvt.k12.ma.us/hiltperk.htm)

### Information Center for Acquired Deafblindness

Generatorvej 2 A  
DK-2730 Herlev  
Denmark  
Phone +45 44 85 60 30  
Fax +45 44 85 60 99  
GSM phone +45 20 12 71 74  
E-mail: [dbcent@dbcent.dk](mailto:dbcent@dbcent.dk)  
[www.dbcent.dk/](http://www.dbcent.dk/)

### Nordisk Uddannelsescenter for Døvblindepersonale

Slotsgade 8  
DK-9330 Dronninglund,  
Denmark  
Tel. +45 96 47 16 00  
Fax +45 96 47 16 16  
E-mail: [nud@nud.dk](mailto:nud@nud.dk)

### Norwegian Central Team for the Deafblind

PO Box 8042  
Dep. N-0031 OSLO  
Phone: (+47) 22 24 81 80  
Tty: (+47) 22 24 81 91  
Fax: (+47) 22 24 81 92  
E-mail: [sentralteamet@sentralteamet.no](mailto:sentralteamet@sentralteamet.no)  
[www.sentralteamet.no/deafblind.html](http://www.sentralteamet.no/deafblind.html)

### ONCE

28006 Madrid  
Tel: 91-431 19 00  
[www.once.es/textos/ingles/index.htm](http://www.once.es/textos/ingles/index.htm)

### Scottish Sensory Center

Moray House Institute of Education  
University of Edinburgh  
Holyrood Road  
Edinburgh, EH8 8AQ  
Telephone: 0131 651 6501  
Textphone: 0131 651 6067  
[www.ssc.mhie.ac.uk](http://www.ssc.mhie.ac.uk)

### Sense & Deafblind International

11-13 Clifton Terrace  
Finsbury Park, London N4  
3SR, United Kingdom  
Tel: +44 171 272 7774  
E-mail: [dbi@sense.org.uk](mailto:dbi@sense.org.uk)  
[www.sense.org.uk/sense](http://www.sense.org.uk/sense)

### Skådalen kompetansesenter Sentralenheten for døvblinde

Postboks 8042 Dep.  
(NO-)0031 OSLO  
Telefon: (+47) 22 24 81 80  
E-post: [sentralenheten@ks-skadalen.no](mailto:sentralenheten@ks-skadalen.no)  
[www.ks-skadalen.no/sentralenheten/](http://www.ks-skadalen.no/sentralenheten/)



# The Deafblind Program at Sibonile School, South Africa

Sam Boshielo is a Deafblind Educator and the National Chairperson of the Committee for the Multihandicapped Blind Persons in South Africa.

## Overview

The unit for the deafblind children at Sibonile School provides services for deafblind learners from different provinces of South Africa. It is one of the only three units in the country. There is great potential for growth because of the uniqueness and the need for deafblind education in the Southern part of the continent of Africa. It is a fundamental human right, endorsed in our country's constitution, that these deafblind learners

**Meshark, learning to use an adaptive mobility device for independent movement. This cane has increased his confidence to move freely about with maximum safety and dignity.**



receive the education and the training they deserve and that their disability does not bar them from opportunity.

## The Learners

The learners have been divided into two groups according to their functional level and age group. This is

to encourage inter-action and group activities while the teacher is busy with individualized instruction or training. The activities include mobility training, gardening, free play, health education, circle time, water play, toilet training, music and taking a nature walk. Communication is part of every activity and there are communication cues for each and every activity.

We are pleased to say that one of our deafblind learners, Namhla Sídina, has now been employed at Sibonile School as a cleaner and is doing well in this new role.

Dora, who lived in an informal settlement shack, suffered terrible burns at an early age and could not walk without support when she first came to Sibonile. The burns caused damage to her face, including her eyes, ears, mouth, nose and hands. After realizing that Dora loved being with other people and, because of this,



**Dora walking independently for the first time in five years.**

would hold tightly on to the trainer while learning to walk independently, I decided to try to use this motivation to encourage her even more. I introduced a two litre bottle, filled with water to our program. When practising walking, I let her hold tight on to the bottle while I held the other end. I then gradually released my hand from the bottle. Eventually Dora started to walk independently for the first time in five years. The bottle has now been substituted by a lighter object – a toy dinosaur.

## Staff Development

There is no specific training for the educators of deafblind people in South Africa. The educators receive guidance and inservice training at the school. We thank the Hilton Perkins Program, and in particular Tom Miller from Perkins School, for having conducted teacher training both at Sibonile and in the United States of America.

## In conclusion

Over the first few years of the existence of this unit, we have realized the tremendous need for training to develop the different people who are involved with deafblind and other multihandicapped blind learners. Parents, house parents and teacher's aides need to learn more about deafblindness so that they can intervene, and support these learners accordingly.



# The School in the Park – an ecological centre for deafblind children

An experiment in teaching outdoors has paid dividends for the children of Caracas in Venezuela. Maria Luz Neri de Troconis, Director of CAISVE, describes a day in the life of this unusual project – the school in the park!

The centre for specialist education for deafblind children in Venezuela (CAISVE) operates in Caracas City. Based within the Parque del Este, it enjoys the most beautiful natural surroundings as a work place made up of every kind of tree, animal, flower, bird, butterfly, leaf, ant, mango, and beautiful people who go out jogging.

CAISVE uses a large zone between shelters 8 and 10 behind the planetarium and the bird zone. Twice a week on Tuesday and Thursdays our students come from Caracas' metropolitan areas and other places of the country.

The families enter the park through Mr Jose's coffee shop, which has a row of benches on the outside. We occupy two shelters with enough space between them, and a concrete table in the middle of each. They serve as classrooms. Between the two shelters there is a crosswalk, the flag square, and the play yard, and fortunately the coffee shop has two restrooms.

Staff members arrive at 7:30 am: Maria Luz (director); Isabel and Norma (teachers); Susana (psychologist); Luz (occupational therapist); Vicki (physical therapist); Carmen and Massiel (assistants);



**Staff and children at school**

Irene (assistant for the deaf); Liliana, Lourdes, Francys and Fatima (volunteers who are friends and relatives of the children). The personnel, along with Nelcida (Carlos Enrique's mother) arrive carrying many knapsacks with most of the teaching material. Because nature provides the rest, we have the best resources there are. As part of our work we meet our fellow employees of the park: "Good morning! A new day begins for every one".

After we meet, we drink the coffee that Leo (Tania's mother) brings and we buy whatever Nelcida brought from the school community's canteen. Then we start organising the working area. We use sleeping bags, mattresses, and different

coloured tablecloths around the shelters to set up the different working areas: music, work, motion, play, etc.

At 8:00 am we meet the parents and students at the entrance; that's when formal work begins!!

From 8.00 am to 9.00 am parents go to the grass or the benches, where they receive training with Irene in sign language or parents-school dynamics with Maria Luz and Susana. The parents-school program is very important for us so that we can assist the children. The objectives are to provide the necessary tools for parents to work along with their children in understanding the nature of deafblindness and their individual child. Psychological





family counselling, home planning, and developing a functional approach to the observation of the children while they work at the centre, are also on the parents timetable.

Later, if anyone asks for Susana the psychologist, she can be found on a bench interviewing a parent, or in a classroom observing the children, or helping the teachers. She is like one of the park's bees. If anyone comes to visit, Maria Luz hosts them at her "office", the entrance bench, where she has a view of everything.

Each member of staff has responsibility for one child and putting the educational program into practice. Communication is the base, using Venezuelan Sign Language (LSV), under the child's hands, close to their face, through gestures, or speaking aloud. From the moment the staff member "touches" the child to get their attention at the start of the day, every member of the team knows how to do their special job in the park setting.

Each helper walks to her "classroom" with her student, taking into account communication and development needs. Each is very different. Norma acts as "sighted guide" to Salvatore and Oscar, and Isael walks along with her students since they are "grown-up" and can make it by themselves to their "classroom". But for most children an interactive approach is used, with staff members adapting to the needs of their young charges.

The students are divided into four groups: maternal, pre-school, school, and vocational. The "maternal" group work in a grass area within three trees, which Vicki has boarded with a blue and yellow phosphorescent tape



in order to stimulate the children visually. A dark blue sleeping-bag is placed in the middle at the "resting zone" for "free time". Over this area, several toys and articles are hung, so that children can look at them while they are lying down. A red mattress represents the "movement area"; a colour printed tablecloth represents the "play and music area".

**A rich routine which includes aspects of high school education, reading, functional maths, and experience through the park are widely used.**

Young children, who have done little before coming to the CAISVE are playing walking and exploring. They are learning to respond to others, developing curiosity and achieving a lot.

"It is a great advantage when they come to us at such an early age!"

"Pre-school" is the largest group of five children. Each student has a "routine" and a finish box (on a bench). The "working areas" are the tables, "movement" happens on a striped mattress. A green toy wagon signals the "play and music area", and the sensory stimulation and resting areas are located on the grass. Communication is the key, and through the individual programmes the children are developing the communication skills.

Two of the children have learnt quickly about communication and the world; hopefully, they will be incorporated to a school for the deaf. One child only attends the centre twice a week, because he lives far away. He is learning quickly, along with his mother. "With him, believing there are no limits is the road toward the development of his potential!"

Norma and Carmen work with the "school group" where typical school elements are included. They have Salvatore, Barbar and Oscar. The children have responded wonderfully to more formal approaches to education. Their "classroom" is organised with each one's routine in a corner: work on the table, play and maths on





the bench, movement and visual stimulation on a yellow mattress outside the shelter. The main work is language stimulation, communication, independence, and work habits.

Then there is the "vocational" group where the students potential is reinforced. Hector, at 20 is able again to communicate through LSV under his hands, or by placing the hands in the visual angle where some residual vision exists. Carlos Enrique who is 19 years old uses LSV near his face, reading and using communication cards. These advances are tremendous. A rich routine which includes aspects of high school education, reading, functional maths, and experience through the park are widely used. They engage in activities according to their age, help others, go shopping, and are prepared for life. They are practical jokers. "Don't say I did not warn you!"

At 9:30 am Fatima "rings the bell" (whistle), the students know it is coffee break. Each one picks up his material and walks to the coffee shop (utilising orientation and mobility techniques). Mr José and his staff have adapted

themselves to our work, allowing us to enjoy this "dining room". There we work on table manners: posture, food tolerance, arrangement of dishes and glasses, napkin use, serving, pouring, picking, cleaning, etc. The children work independently and together with their teacher. After lunch there is free time!

After free time, we continue with our activities. The school and vocational groups attend the park's library two hours a week; there they engage in appropriate activities.

It is 12 noon. The mothers arrive to collect their children. "The day is over, it is time to go home, you did a great job, a kiss...!". We see them disappearing until the following day. The team stays longer to talk about the day...*It was worth it!*

In CAISVE each student receives an integrated program. Our philosophy is that "they are children first and deafblind second", so that each child's personal characteristics must be taken into account. Realistic assessment is very important; as is the focus on the functional, ecological, and natural.

## How did it start?

The idea of working at the Park, emerged from the desire to work with the children, when the CAISVE's family began its meetings in November 1995. Everyone can see the results were magic. The best proof is the children's attendance, even when it is raining.

We expect soon to have our own building, where we will work every day with the students. But the Ecological Centre for the Deafblind will not disappear. We will continue coming to the Park on Tuesday and Thursday, since we learn and experience what we could never find within four walls – to share this beautiful environment with children of the same age, the local community, and society at large.

We acknowledge support from Professor Beatriz Nunez de Baez (National Director of Special Education), Elisa Estezo de Valero (Visual Deficiency programme), Magaly de Henrueez (Foundation for the Development of Special Education), Juan Kujawa (Cacao Municipality), Socieen (Deafblind from Venezuela), and Raquel Casadiego (Special Education Department, Educational Zone No 1). Also Steve Perreault, Graciela Ferioli, Maria Bove and Vicki Brennan (advisors from the International Hilton/Perkins Program, which supports CAISVE). Thank you to all the children, staff team, parents and volunteers.



## Networks

### ACQUIRED DEAFBLINDNESS NETWORK

c/o Anneke Balder  
Stichting Dool-Blinden  
c/o SDG  
Christian Krammlaan 2  
3571 AX Utrecht  
THE NETHERLANDS  
Tel: +31 - 30 -  
276 9970/0459  
Fax: +31 - 30 -  
271 2892

### COMMUNICATION NETWORK

c/o Jacques Souriau  
L'Habit d'Or  
Marigny - Brizay  
86380 Vendevre 4  
FRANCE  
Tel: +33 - 5 -  
49 52 09 24  
Email: souriau@interpc.fr

### CONGENITAL DEAFBLINDNESS IN ADULTS NETWORK

c/o Bob Snow  
Sense North  
122 Westgate  
Wakefield WF1 1XP  
UK  
Tel: +44 - 192 -  
420 1778  
Fax: +44 - 192 -  
436 6307  
Email: bobsensen@aol.com

### EURO UNIT/STAFF DEVELOPMENT NETWORK

c/o Lieke de Leuw  
IvD International  
Instituut voor Doven  
Theestraat 42  
5271 GD Sint-  
Michielsgestel  
THE NETHERLANDS  
Tel: +31 - 73 -  
5588111  
Fax: +31 - 73 - 5517897  
Email:  
ivd.international@rdt.ivd.nl

### EUROPEAN USHER SYNDROME STUDY GROUP (EUSSG)

c/o Mary Guest  
Sense  
11 - 13 Clifton Terrace  
Finsbury Park  
London N4 3SR  
UK  
Tel: +44 - 171 -  
272 7774  
Fax: +44 - 171 -  
272 6012  
Email:  
MGuest@sense.org.uk

Dbl formally recognised four new networks seeking recognition. They were the European Deafblind Network (EDbN), the Employment Network, the Nordic Culture Network, and the Interpreting Development Network.

## EDbN (European Deafblind Network)

The aim of EDbN is to improve the situation of deafblind people in Europe with the objective of achieving their equal rights and full participation in society, and to be a European forum for the exchange of knowledge and experience in the area of deafblindness. EDbN brings together national organisations of deafblind people, their families and professionals working in the field to provide an effective voice for them within Europe and to co-ordinate a variety of activities on their behalf. Their activities include: an annual Seminar in conjunction with the Council meeting; co-operation with other European Disability organisations as a member of the board of the European Disability Forum (EDF); a newsletter 1-2 times a year in print, disk and internet versions; participation as a partner in different transnational EU projects; other seminars and conferences.

## Employment

The focus of the Employment network has been on a number of issues relating to the employment of deafblind people. The aim of the

network will be to ensure that employment issues relating to deafblind people continue to be properly considered by organisations and individuals throughout the world. It will seek to influence relevant bodies, both within and outside the deafblind world, to ensure that deafblind people have a right to employment and continue to receive employment opportunities. Activities undertaken so far include more than ten transnational meetings across Europe, international exchange visits involving deafblind people looking at employment situations in other countries, a European survey of good practice, national and international conferences on the subject of employment, a lobbying day at the European Union, lobbying of other national and international decision makers, the circulation of a specialist newsletter on employment and dissemination of information throughout the world.

## Nordic Culture Network

The objectives of the Nordic Culture Network is to offer cultural activities for congenitally deafblind adults from all the Nordic countries. For example one of the members, the Nordic Art School, offers congenitally deafblind people the opportunity to work and develop their creative talents, to learn, experience, express themselves and communicate with the outside world in a new and different way. Planned activities include courses on sculpture, stone-masonry, drama and music as well as involvement in relevant conferences.

## Interpreting Development Network

The aim of the Interpreting Development Network will be to ensure that issues concerning the training and development of services will be considered by organisations, agencies and individuals at an international level. One main aim will be the creation of policy and the defining of good practice through curriculum design, and models of training and service delivery. Activities planned for the future are the organisation of a symposium, distribution of materials, identification of good practice for education, development of training for deafblind interpreters, and the development of guidelines.

It has been agreed that **William Green** will take on the role of Network development and will be the contact person for networks. The benefits of becoming a recognised network include the increased chance of funding, finding project partners, distribution of information and a chance to influence Dbl.

It has been noted that there is still a very strong European bias in the Networks and Dbl would very much like to encourage wider participation.

For further information on how to become a recognised network please contact William Green at:

Lega del Filo d'Oro,  
Via Montecerno 1  
60027 Osimo (AN), Italy  
Tel: +39 - 71 - 72451  
Fax: +39 - 71 - 717102  
Email: green.lfo@usa.net



## European Usher Syndrome Study Group

July 1997, Madrid, saw the last full (and it was full) meeting of the European Usher Syndrome Study Group.

With over 90 participants, some attending for the first time and requiring basic information, it became apparent that the original concept of informal study in a small group setting was getting harder to achieve given the increasing interest in the area.

To meet the growing needs of people with Usher and their families, it was proposed to form a new European Usher Network. The purpose of this group is to link in with groups of people with Usher and families across Europe, to stimulate groups to form in countries where there are none, to share information about Usher and to provide awareness for Usher across European boundaries.

### Progress since Madrid

Since the Madrid Conference a small steering group drawn

from Denmark, Germany, Spain and the UK has met four times to take these ideas forward.

### What next for the Study Group?

Since 1997 there has been much activity on the Usher front. Tactual communication and communication methods with deafblind people were the main topic at a conference held in Holland in June 1999.

Genetic research has advanced to the extent that there are now 6 Usher genes located for Type 1, 3 genes for Type 2 and 1 for Type 3. In the UK we are aware that numbers of people with Types 2 and 3 are increasing. Numbers of Usher children with cochlear implants are also increasing. It is now time for another gathering in order to share knowledge.

### Ideas

It is possible for us to meet in Holland in 2001 just before or after the 5th European Dbl Conference from 24-29 July. If we met then we would hold a Study Group over two days, and if possible, in the same venue.

At this stage it would be most helpful in the preliminary planning stage to receive views from readers about topics of study and themes which the EUSSG could take up. Please send you views to:

Mary Guest  
Principal Research  
Officer – Usher  
Sense  
11-13 Clifton Terrace  
Finsbury Park  
London N4 3SR

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

## The CHARGE Network

The recent XIth World Deafblind Conference in Lisbon, Portugal was the ideal place to put the CHARGE Network onto a more formal footing. David Brown, Head of the Family Centre, Sense and David Levey, CHARGE Development Officer, Sense went to Lisbon to establish firmer links with their international partners. These links first began at the previous Dbl World Conference in Argentina in 1994 when David Brown gave a presentation about the changing population of children with deafblindness, during which he mentioned CHARGE only very briefly. At the end of his presentation several delegates came to him with requests for further information about CHARGE, and from this a small and informal network began.

Over the past four years David Brown has attended CHARGE conferences in the USA, and in Australia and New Zealand, and after these he has mailed articles and other information to people in this informal network – about 10 people in 8 different countries. Over the years there has been concern about the need to link CHARGE more closely with the world of deafblindness. Although there are a small number of national CHARGE support groups around the world few of them have very close links with specialist deafblind

groups or organisations.

In Lisbon a dream came true when the first ever CHARGE Network session at a Dbl conference was held. The morning was attended by over 70 delegates from at least 18 different countries and included parents, teachers, doctors, psychologists, and residential workers. David Brown made the opening presentation giving an overview of CHARGE and showing video clips to give an idea of mobility patterns in young children with CHARGE. Then teacher Berit Ronnassen joined Maria and Lars



Peterson from Sweden who talked about their son, David, who has had a cochlear implant: this was a very moving presentation and included lots of very clear "before and after" video. After the break Deborah Chen from the USA gave a presentation about CHARGE in her home state of California followed by three case studies of older children with CHARGE.

In the final part of the morning David Levey, led a discussion about setting up a more formal CHARGE Network recognised by Dbl, and about what the aims and scope of such a Network might be. After an interesting discussion it was agreed that a Development Group would be formed initially consisting of Patrizia Ceccarani – Italy, Hanne Pitroff – Germany, Samia Robin – France and with David Levey who would act as the first point of contact for the group. David agreed to approach the CHARGE Foundation in the

USA, and the Australasian CHARGE Support Group to ask them to nominate representatives to join the Development Group, which will then draft a proposal to submit to the Dbl Council to ask for Dbl recognition. One of the ideas put forward was for the Development of a website, and another was to examine ways of encouraging and facilitating research into various aspects of CHARGE.

At the very end of the session there were many questions about CHARGE. Many delegates gave contact details so they could be included in the ongoing development of the Network. There was great interest in the fact that Sense is planning to organise a CHARGE conference in the UK in 2001.

**Footnote:**

Two years ago David Brown wrote the following about children with CHARGE:

*"I know of no identified sub-group within the population of people with multi-sensory impairment who have so many medical problems, of such complexity and severity, and with so many hidden or delayed difficulties, and yet no sub-group has shown such a consistent ability to rise triumphantly above these problems."*

People with CHARGE offer inspiring examples to us all and also offer a range of fascinating insights into the nature and challenges not just of deafblindness but of multi-sensory impairment. For far too long they have been missing out on appropriate deafblind services and support. We hope that the CHARGE Network will help to feed information about CHARGE into the deafblind field, and in its turn create more deafblind awareness and ideas into the world of CHARGE.

**David Levey**

## Employment Network in Lisbon

A very successful Employment Network Day was in Lisbon. The Employment Network, which is officially recognised by Dbl, is the result of two international programmes supporting employment opportunities for deafblind people that have been funded by the European Union's European Social Fund Horizon Programme over the last four years. These programme have involved partners from Italy, Sweden, Denmark, Portugal

and the UK – and additional activities have also included the involvement of organisations such as the European Deafblind Network. As a result of widespread dissemination we have also found interest in this subject in other parts of the world such as Latin America, Eastern Europe and India.




The day was attended by over 70 participants, and over 400 participants attended a plenary where Richard Hawkes outlined the project and the outcomes of the

network meeting. As well as presenting the national and transnational elements of the HORIZON work, the purpose of the network morning was to share information on adaptation of materials, the PHANTOM programme and the future of the HORIZON project.

**For more information please contact Tamar Underhill at Sense International.**



## Communication Network

<p><b>L'émergence de la communication - 2<sup>e</sup> partie</b>  <b>The Emergence of Communication - Part II</b>  <b>La emergencia de la comunicación - 2<sup>a</sup> Parte</b></p> <p>Cours international du 11 au 14 avril 1999</p> <p>Ce livre regroupe les principales conférences et une courte présentation des ateliers du second cours. Il traite de la façon dont l'enfant sourd-aveugle et son partenaire utilisent des gestes naturels comme base de création d'un sens partagé et d'un premier vocabulaire partagé.</p> <p>This book contains the main lectures and a short presentation of the workshops of the second course. It focuses on how the deafblind child and his partner can use the natural gestures as a basis of shared meaning and first shared vocabulary.</p> <p>Este libro reúne las principales conferencias y una breve presentación de los talleres del segundo curso. El trata de la forma como el niño sordo-ciego y su interlocutor utilizan los gestos naturales como base para crear un significado compartido y un primer vocabulario compartido.</p>	<p><b>Actes</b></p>	<p>Deafblind International (Dbi) - Working Group on Communication          Centre national d'études et de formation pour l'enfance inadaptée (CNEFEI)          Suresnes - France</p> <p>L'émergence de la communication          chez les personnes atteintes          de surdi-cécité congénitale</p> <p>The Emergence of Communication in          Persons with Congenital Deafblindness</p> <p>La emergencia de la comunicación          en las personas sordo-ciegas congénitas</p>  <p>International Courses          23 - 26 June 1996          11 - 14 April 1999          CNEFEI - Suresnes - France</p>   <p>Avec le soutien de la Communauté européenne</p>
<p><b>L'émergence de la communication - 2<sup>e</sup> partie</b>  <b>The Emergence of Communication - Part II</b>  <b>La emergencia de la comunicación - 2<sup>a</sup> Parte</b></p> <p>Cours international du 11 au 14 avril 1999</p> <p>Cette vidéo montre comment des expressions corporelles peuvent créer une base permettant aux deux partenaires de s'engager dans une négociation de sens partagé et dans un premier vocabulaire partagé.</p> <p>This video focuses on how the body expressions can create a base for both partners to engage in negotiation of shared meanings and a first shared vocabulary.</p> <p>Esta videocassete muestra de qué forma las expresiones corporales pueden crear una base que permite a los dos interlocutores de comenzar y de compartir una negociación en relación con el significado, y también, de compartir un primer vocabulario.</p>	<p><b>Vidéo</b></p>	

## The Emergence of Communication in Persons with Congenital Deafblindness

### The Development of Communication.

#### What is new?

*The book and video of the International Course of 23-26 June 1996*

#### The Book: The Emergence of Communication

This book contains the main lectures of the International Course: "The Development of Communication - Part 1". The purpose of this course was to address communicative development from two complementary viewpoints: Non-handicapped children and People with Congenital Deafblindness.

**Cost: 100 F**

**The Video:** This video is the result of a collaboration between various professionals in several European countries and indirectly contributed to by many deafblind children and their families.

The video focuses on how motivated interactive experiences between the deafblind child and his partner can offer the right conditions for the child to create natural gestural expressions.

**Cost: 150 F**

### The Emergence of Communication - Part 2

*The book and video of the International Course of 11-14 April 1999*

**The Book:** This book contains the main lectures and a short presentation of the workshops at the second course. It focuses on how the deafblind child and his partner can use the natural gestures as a basis of shared meaning and first share vocabulary.

**Cost: 120 F**

**The Video:** This video focuses on how the body expressions can create a base for both partners to engage in negotiation of shared meanings and a first shared vocabulary.

**Cost: 150 F**

For further information or to make a purchase, please contact:

Centre National de Suresnes  
 58-60, avenue des Landes  
 92150 Suresnes  
 France





## SWITZERLAND

**The Swiss National Association of and for the Blind (SNAB) reports**

The Support Centre for the Deafblind of the Swiss National Association of and for the blind, SNAB, places voluntary workers to support deafblind and hearing-and-vision-impaired people on training courses and excursions etc. but also to act as personal companions and interpreters. The SNAB regularly organises seminars on subjects related to deafblindness in order to support the group of voluntary workers and to offer them further training.

This year the subject was "communication" and in April a lively bunch of 22 expectant participants from different corners of the German-speaking part of Switzerland arrived at the seminar centre Boldern, situated above the beautiful Lake Zurich.

Four speakers introduced the **aspects of**

**communication** and the subsequent workshop study areas: the development of communication in the course of cultural and human history: the links between communication style and the understanding of one's role: communication related to the body and sensuality and communication; encouraging co-ordination and comprehension in human relationships Two dual sensory-impaired speakers very impressively demonstrated the difficulties of communication resulting from the loss of key senses or the use of incompatible forms of communication.

Nel Hautmann, Ruth Fries, Charles Lindegger, Norma Bargetzi, Mrs M Th. Muller and Beat Marchetti led the workshops with great skill.

During the breaks, everyone was busy chatting

with friends and colleagues, experiences were exchanged and social contacts revived. The wonderful green surroundings enticed everyone to relax for a moment in the wonderful countryside beside the Lake.

The participants were very interested in and committed to the workshops and therefore everybody found working with this broad subject very rewarding and stimulating.

Further information can be obtained at the following address:

SNAB Office:  
Taubblindenberatung SZB;  
Cramerstrasse 7,  
CH-8004 Zurich,  
Switzerland.

Tel./Fax: +41-1-2412111;  
E-mail:  
szb.tbb1-zuerich@tic.ch

## NEW ZEALAND

**New Zealand is about to host the 7th Helen Keller World Conference and the first General Assembly of the World Federation for the Blind. Jan Scahill, the conference convener writes:**

This will be an exciting and challenging occasion – both these key events taking place at one time! The action will

happen in Auckland, New Zealand between the 7th-12th October 2001 and the theme is "What it means to be deafblind – identity, rights unity".

As the theme indicates, this will bring recognition of the needs and services of deafblind people internationally, identifying them, putting forward their rights and bringing greater unity to those who have this unique, dual disability and their fellow citizens.

We down here in southern parts of the world need the support from those of you who have worked for many years and in many countries throughout the world improving services for deafblind people. So, come and give us some assistance and lets work together to build strength for all of us!

Jan Scahill can be contacted at

jscahill@rnzfb.org.nz or at

PO Box 14-076  
Tauranga  
New Zealand







## AUSTRALIA

**Sharon Barrey Grassick sends exciting news of some new resources:**

Western Australia Deafblind Association (WADBA) has just released its deafblind awareness and training video, **ASSUME NOTHING: An Introduction to Deafblindness.**

Six clients of WADBA are featured; from the very young to adults, all with varying degrees of hearing and vision loss. Three of the children and one adult are congenitally deafblind from various causes and two of the adults have acquired deafblindness, including one with Usher Syndrome.

The focus is on what

people who are deafblind CAN do, given appropriate supports and services.

ASSUME NOTHING is a 22 minute open captioned video and issues presented include communication, early intervention, education, technology, career choice, recreation, independence and interpreting.

WADBA believes that by assuming nothing, it will never place a limit on what any individual might achieve and is happy to say that feedback from reviewers of this video has been excellent.

So if you'd like to see it for

yourself and use it in your services please contact

WA Deafblind Association  
PO Box 14  
MAYLANDS  
West Australia  
Australia 6051

Its available in PAL format \$25.00 and NTSC format \$30.00, plus \$5.00 postage within Australia, and \$10.00 postage overseas format.

or for bankcard payment, FAX (08) 9271 3129, or email [wadba@nw.com.au](mailto:wadba@nw.com.au) for an order form.

## CANADA

### McInnes House Enters A New Phase

**McInnes House, the facility developed in Brantford, Ontario for adults with congenital deafblindness, is proud to report an exciting new phase of its operation.**

Thanks to the Lions Club, through their sponsorship of Lions for Deaf Homes, a new facility will be constructed this year. This new building will accommodate up to 15 individuals in 1, 2 and 3 bedroom self-contained apartment units located on one floor.

The new building will replace the three story apartment style building purchased by the Lions Club in 1983 to accommodate nine young adult individuals with deafblindness

This independent living facility was named McInnes House, after John McInnes, whose foresight was the initial driving force for the facility, and was its first Executive Director in 1983. The facility

initially was designed as a model for independent living (with Intervention), for individuals with congenital deafblindness. This model was ultimately adopted throughout Canada and adapted in other countries.

John and Jacquie McInnes were on hand in Brantford on

September 18, 1999 and officiated with members of the Lions Club, residents of the facility, administrators and volunteers in the official sod turning ceremony for Phase 2 McInnes House. Residents are expected to move into their new home early in the year 2000.







CANADA (continued)

New Book on Deafblindness Recently Published



The publication (ISBN 0-8020-4242-2 (cl)) is available from the University of Toronto Press (London) for £56.25.

On September 18, 1999 the University of Toronto Press published the long awaited book edited by John McInnes titled 'A Guide to Planning and Support for Individuals Who Are Deafblind'.

John McInnes's ground breaking book 'Deaf-Blind Infants and Children: A Developmental Guide', co-authored with J.A. Treffry and published by The University of Toronto Press in 1982, focussed on the initial stages of working with the congenital deafblind child. In the preface of this publication, John McInnes indicates that "the purpose of this book is to address the problems faced by parents, intervenors, para-professionals, and professionals who work with infants, children, youth, and adults who are congenitally or early adventitiously deafblind".

"Just as McInnes and Treffry's Deafblind Infants and Children helped to change the approach to and the perception of deafblind children, this collection will assist in fostering a new approach to the education of and support for older children, youth, and adults who are deafblind. An essential part of this process is to set forth standards for program development, implementation, and evaluation, which this volume aims to accomplish. It will make an essential contribution to the expanding field of services for the deafblind population of all ages and to the improved understanding of parents, family members, and professional who support them". (Introductory remarks on the book's jacket).

This truly is an international publication. Twenty-five leading experts in the field of deafblindness from around the world, many who are well known to

Deafblind International, contributed to this important collection. A sample of the seventeen chapters and their authors include: Intervention (John McInnes); Communication (Inger Rodbroe and Jacques Souriau); Neurobiological Development and Cognition (Douglas Greenens); Social and Sex Education (Tom Miller); Family Viewpoint (Norman Brown and Gini Cloke); Community-Based School Option (Carolyn Monaco and Linda Mamer) and Intervenor, Teacher and Consultant Training (Margot McGrath-Harding, William Thompson and John McInnes). Bryndis Viglundsdottir offers a final chapter titled Final Thoughts.

The book is dedicated to the memory of Margot McGrath-Harding, a leader in the field of Intervenor training in Canada, who died in a tragic accident in June of 1998.

Stan Munroe

Canada Accepts the Challenge to Host Dbl World Conference in 2003

Three members of the Canadian Deafblind and Rubella Association gleefully accepted the decision by Dbl World Council that the 13th World Conference be staged in Canada in 2003.

Stan Munroe, Linda Mamer and Carolyn Monaco, while addressing the General Assembly on the last day (July 25) of the Portugal Conference, indicated their appreciation to Dbl Council and Management Committee for the trust they have placed on the CDBRA to organize the next conference. They congratulated Antonio Rebelo, 12th Conference Chair, for the wonderful hospitality and experiences provided by the Portugal Conference Planning Committee during their stay in wonderful Lisbon-Estoril.

Suggesting that

conferences should not be viewed as competitions, Stan, Linda and Carolyn promised that Canada would provide its own brand of hospitality and experiences, as well as a program fitting Dbl conference standards.

They welcomed the world to visit Canada in 2003 and suggested that visitors take the opportunity to see some of the many tourism opportunities that Canada provides. "Don't just come for a good time, come for a long time", Stan Munroe appealed to the audience.

Following their address,

the Canadian delegates accepted, on loan, the Stone Carving from Lex Grandia. Lex donated his sculpture to Dbl in 1992 on the condition that it reside with the World Conference organizers until the next conference. The sculpture had been on loan to the Portugal Committee at Casa Pia de Lisboa since the Cordoba Conference in 1995.

The Canadian delegates announced that the conference will be held August 05-10, 2003 at the Delta Meadowvale Hotel and Conference Centre in Mississauga, Ontario.





## EDbN

**Lex Grandia reports in the EDbN Newsletter**

The five chairpersons of the Nordic Deafblind organisations who meet every year, announced this year that they have founded a European Deafblind Union.

The aim of the Union is to develop co-operation between the associations of

deafblind people in all European countries, and at the same time aim to improve the quality of life for all deafblind people.

Membership of the Union is restricted to those associations of deafblind people whose decisions are

made by deafblind people themselves. An interim committee for the new organisation was also elected. Ove Bejsnap from Denmark was chosen as its Chairperson. The EDbU will hold its first congress in 2002

## NUD

**Anny Koppen in the NUD Newsletter describes the busy and successful year the NUD has had but highlights changes that are happening...**

There are changes in the professional field of deafblindness. In the Nordic countries the services and facilities are being decentralised, more and more. The aim is get support provided as near to home as possible. This means that some of the larger institutions will be discontinued and children and young people

will receive their schooling much close to home. This means that new services will be developed to support individual deafblind people and some of the professionals may only meet a single deafblind person in their professional lifetime. The NUD staff are discussing how they can maintain and further develop expertise in

the field of deafblindness now that the large specialist environments are disappearing.

An institution like NUD has to be alert to the developments as they happen and generate the dialogue and relationships necessary to continue to support the staff who in turn will support the lives of deafblind people.

## INDIA

Dr Bhushan Punani from the Blind People's Association reports that the Rehabilitation Council of India has decided to include deafblindness in the course curriculum for the primary as well as secondary level teachers for the Visually Impaired. Mr. Madhukar Choudary of the National

Association for the Blind and Dr Punani argued and convinced members of the task force of the RCI to include deafblindness in the curriculum. About 20 hours will be devoted in teaching deafblindness to the teachers.

## ROMANIA

**Cristiana Salomie from Romania, where she works for Sense International, reports:**

"We were absolutely delighted when in June of this year, the Government of Romania agreed to the opening of two units for deafblind children. In September the dream became a reality and the units, one in Cluj and the other in Bucharest, are now in

operation with a total of 8 children now receiving individual education. We hope that the units continue to grow and thrive and wish all the staff working with the children good luck.



In the seventh in our occasional series on causes of deafblindness, this edition examines

## Alström Syndrome

### Introduction

Alström Syndrome (AS) was first described by Carl Henry Alström of Sweden in 1959 in a paper he co-authored with B. Hallgren, I.B. Nilsson and H. Asander<sup>1</sup>. Alström Syndrome is a hereditary and very rare, life threatening disorder which begins to take effect during early childhood. At present there are 104 children and adults world-wide known to have this condition which can be quite variable and have an age-related progression.

### Diagnosis

Alström Syndrome is autosomal recessive and even though it has been mapped to chromosome 2p13, the gene responsible for the disorder has not been identified. Prenatal tests are not available for Alström Syndrome but diagnosis is made when particular features of the syndrome are observed.

In clinical medicine, diagnosis is made when four out of five principal features of AS are present. These are degeneration of the retina (retinopathy) at an early age i.e. under 1 year, which is usually first noticed as involuntary eye movements (nystagmus) and/or light sensitivity (photophobia). In addition, infantile obesity, cardiomyopathy (infantile or adolescent), mild to moderate sensorineural hearing loss may also be observed in early childhood, and type 2 diabetes mellitus or high levels of insulin in the blood (hyperinsulinemia) usually begin in adolescence.

### Presentation of features

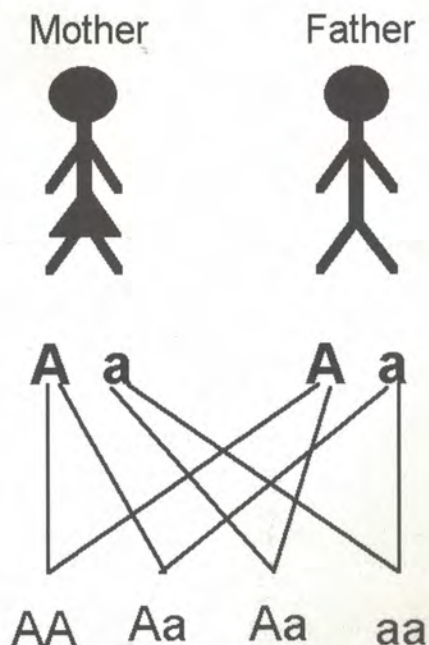
Alström Syndrome tends to progress in a particular order with one of the first signs being either infantile dilated cardiomyopathy and/or nystagmus and photophobia. Both can occur as early as 1-3 weeks of age. Obesity is usually seen beginning in the first year or two of life. Hyperinsulinemia/insulin resistance has been documented in children as young as 2 years old, but there is not a lot of information about this yet. Sensorineural

hearing loss occurs at approximately 4 - 6 years of age. Diabetes may develop, usually after adolescence. There may be kidney and liver problems too.

### Pattern of inheritance

Alström Syndrome is autosomal recessive which means that for a child to have the condition they must inherit one mutated gene from their mother and one from their father (see diagram).

Diagram to show pattern of inheritance for Alström



### Key:

		<i>Probability</i>
<b>A a</b>	Parent carriers of Alström gene	
<b>AA</b>	Unaffected child	25%
<b>Aa</b>	Unaffected child carrier of Alström gene	50%
<b>aa</b>	Affected child with Alström syndrome	25%



### **Syndrome**

As the diagram shows, for each pregnancy there is a probability of 25% that parents who are carriers of the mutated gene will have a child with Alström Syndrome. There is also a probability of 25% of having an unaffected child who will not be a carrier and a probability of 50% that they will have unaffected children who are carriers of the gene. Boys and girls have an equal chance of inheriting the gene responsible for Alström Syndrome.

In 1997 researchers at the Jackson Laboratory in Bar Harbor, Maine, USA located the gene for Alström syndrome on chromosome 2. Genetic research is being conducted world-wide to identify the mutation responsible for such devastating effects on multiple organ systems. Research is also taking place in Canada, United States of America, France, Italy and the United Kingdom.

### **Prognosis**

Children with Alström Syndrome can and do lead full and productive lives. Even though there is no cure for Alström Syndrome treatment/therapy is possible to alleviate some of the symptoms experienced by those that have the condition. For instance, diabetes mellitus may be controlled with medication combined with diet and exercise, and the use of hearing aids can help children and adults cope with hearing loss.

### **World-wide distribution of Alström Syndrome**

As stated earlier there are 104 known children and adults with Alström syndrome who live in 16 different countries around the world. Most of these are in developed countries such as Canada, the United States of America and the United Kingdom – the latter having the largest group of diagnosed AS children and adults.

The distribution of Alström Syndrome affected individuals mostly seen in developed countries highlights the concern that there are probably many more AS cases in developing countries going undiagnosed, and this may be attributable to lack of information about the syndrome. Undiagnosed children could be missing out on vital medical treatment and educational approaches appropriate to their needs.

### **International Contacts**

The Jackson Laboratory, Maine, USA is currently leading the research into identifying the genetic mutation. The international Society for Alström Syndrome Families (SASF) is also based in Maine, USA and has a board of directors consisting of people from Canada, USA and the UK. Branches are located elsewhere within the United States and one has recently established in the United Kingdom while another is just being formed in Canada.

Jan Marshall  
The Jackson Laboratory  
600 Main Street  
Bar Harbor  
Maine 04609 - 1500  
USA  
jdm@jax.org

International SASF  
14 Whitney Farm Road  
Mount Desert, Maine 04660  
USA

Kay Parkinson  
Alström Syndrome - UK  
49 Southfield Avenue  
Paignton  
South Devon  
England, UK. TQ3 1LH  
alstrom@  
syndromeUK.freeserve.co.uk

Randy Douglas  
Alström Syndrome - Canada  
Ottawa, Canada  
rdouglas@glen-net.ca

### **World Wide Web Information**

<http://www.jax.org/alstrom>  
<http://www.elom.co.uk/alstrom>

**Fiona Hall-Jones**  
November 1999

- 1 Alström CH., Hallgren B., Nilsson IB., Asander H. (1959) Retinal degeneration combined with obesity, diabetes mellitus and neurogenous deafness. A specific syndrome (not hitherto described) distinct from Laurence-Mood-Biedl syndrome. A clinical endocrinological and genetic examination based on a large pedigree. Acta Psychiatr Neurol Scand 34(Suppl. 129):1-35.



**This issue sees a new section to introduce you to professionals and friends across the world. These individuals are making a major contribution to deafblindness in their home countries and here we meet some hard working colleagues from Canada and Eastern Europe...**

**They will be surprised themselves to find their photographs here!**

**Thanks to Dennis Lolli and Stan Munroe**

**Patricia Curtis**



Patricia has the distinction of combining the difficult roles of administrator

and parent. She is the parent of Andrew, an adult with congenital rubella syndrome.

She is the Executive Director of the New Brunswick Chapter of the Canadian Deafblind and Rubella Association, an organization she helped develop into a leading service provider for persons with deafblindness. Her responsibilities include working closely with provincial agencies and organizations to provide support for families and provide Intervenors to individuals who are deafblind.

Her first career was as an elementary school teacher in New Brunswick and Ontario. Patricia was also one of the founding parents who formed the CDBRA almost 25 years ago.

**Nazar Strojko**



Nazar is deafblind, but he refuses to let his disabilities hold him

back. The 55-year-old has flown a small plane, with the help of a pilot sitting next to him. When he skis he wears vibrators, controlled by an instructor, which help him to change directions or stop.

Nazar began to lose his sight and hearing when he was only 4 and living in Poland. At 23 he came to Canada and taught himself English, using a dictionary.

By age 35 he could no longer read books unaided. He is able to read using a Closed Circuit TV Reader. He has also learned to use Braille.

Nazar credits the staff at Rotary Cheshire Apartments in Toronto for his happiness and independence. When he lived on the 20th floor of a high rise building there were many people around, but no one to communicate with him. Now he can do so much more because of the daily services of an Intervenor to access people, places and information.

**Cherry Bulmer**



Cherry is a the parent of Cara, whose deaf-blindness was

caused by congenital rubella. She has been a tireless advocate for those who are deafblind, especially promoting Intervention. She is editor of Intervention, the newsmagazine of the CDBRA, a post she has held since the publication began. She is the co-author (along with her daughter JoAnn Newbery) of WINGS, A Model for an Integrated Lifestyle. She also manages Intervenor services for Cara, who lives independently, with Intervention.

Cherry is a trained elementary school teacher and is currently employed as an interpreter for a student attending a public school in Dorchester, Ontario. She sits on the Board of Directors of CDBRA and the Planning Committee for Dbl 2003.

**Vantha Chik**

Vantha has a rather interesting personal history to complement his deafblindness disability. He was born in Cambodia during the period of major upheaval almost 30 years ago. While living in refugee camps he lost contact with his family. He was subsequently adopted by a Canadian family from Ottawa. Vantha graduated from the W Ross Macdonald School and completed a three year business course at Mohawk College.

Surprisingly, while living in Canada he became re-united with his natural mother. This resulted in making contact with his natural father, still living in Cambodia. He independently planned a trip to Cambodia, upon which he became married to Pahteymas. During a subsequent trip to Cambodia he fathered a daughter; but the family was still not united.

Thanks to Intervention, Vantha worked successfully with immigration officials for several years to have his wife and daughter immigrate to Canada. These efforts became a reality earlier this year. The family has subsequently re-located to northern Ontario, where Vantha continues to search for employment, with the assistance of his Intervenors. He represents disabled persons on a volunteer a Local Planning Coordination Group, which assists in obtaining employment for disabled persons, like himself.

Vantha speaks highly of the role of Intervenors to assist him with his search for employment and while he cares for his daughter Yarea while his wife is at school.



## Janka Sarisska



Janka Sarisska is the Director of the Evangelical Diacony School for

Deafblind Children in Cervenica, Slovakia. Through her strong personal efforts and support from the Evangelical Church, this school has grown from four rooms which serves as living and education space for two staff and three children in the village of Svidnik, into a model program serving up to 15 children out of two new buildings in Cervenica. Janka continues to work not only for the education of her students but in support of the skills which her staff bring to their job. Her energy and commitment were influential in the implementation of a 5 year course of study in conjunction with Comenius University, the Slovak Ministry of Education and the Hilton/Perkins Program. This effort will result in the official credentialing of the 28 instructors for children with deafblindness and multiple disabilities in June of 2000.

While the focus of her school, now going into its eighth year, is on education, she continues to raise regional and national awareness as she advocates for a range of services that will follow the needs of deafblind children into adulthood. She also is a strong supporter of the deafblind parent organization, which use the school as its home base. Her efforts are bearing fruit as professionals within Slovakia constantly visit her school to learn about the education of deafblind children. She is also frequently hosting

professionals from other countries who wish to observe a wonderful educational program for deafblind children. Janka's love of her students is rivalled only by the energy she brings to their total program.

## Galina Epifanova



Galina Epifanova has been involved with the Deafblind Children's

Home since its beginnings in Sergiev Posad, Russia. She began her work in the classroom and is now the Chief Director of the Children's Home. Over the years, the school has grown from 35 children to its current 130. It may well be the largest education program for deafblind children in the world. As you may imagine, to achieve growth and maintain quality has become more and more difficult for the Children's Home. Any visitor is struck by the way Galina is constantly and comfortably moving in and out of classrooms: discussing lessons and solving problems with teachers and children. She knows each child and whenever she begins to communicate with a student, their face lights up.

Galina is truly the major factor in keeping "everything" together at the Children's Home. She does this while maintaining a focus on the needs of the students and juggling the needs of staff as well as visitors. Because of the limited support this program receives from Russia's central government, Galina finds herself more and more in the role of development officer, working effectively with NGO's and

potential donors, but never losing her child centred focus.

Her presence at the Deafblind Children's Home is one of the major reasons that the staff stays vibrant, and that the education program addresses the needs and abilities of all 130 children.

## TRIBUTE

### Dr Edward Waterhouse



Dr Waterhouse with Helen Keller

We are saddened to announce the recent death of Dr. Edward J. Waterhouse, who passed away in his home in the state of Maine last week. He was 97 years of age. He was Director of Perkins from 1951-1971, and served the school for a total of 40 years in various capacities.

As many of you will know, Dr Waterhouse helped to establish Deafblind Programs and Services worldwide at a time when no-one else was doing so. He helped to expand the Teacher Training Program (now the Educational Leadership Program) to serve many hundreds of overseas professionals. During his tenure, the Perkins Braille as we know it today was introduced to the world.

Dr Waterhouse was a good friend and colleague to many of us at Perkins, and we will always remember his friendship and strong leadership abilities. Professionals in deafblind education, blind education, and Deafblind International owe him a debt of gratitude for all his contributions to our fast-growing field.

Mike Collins and Kevin Lessard



## **Co-creating Communication – with congenitally deafblind persons 17–23rd June 2000**

The EUCO Unit – The European Coordinating Unit for Staff Development in Deafblind Services – has decided to offer a training course on the development of communication in congenitally deafblind persons. The Nordic Staff Training Centre for Deafblind Services will organise the course.

### **Target Group**

The course is primarily offered to key staff who work with congenitally deafblind people, such as staff with supervising and coordinating functions.

### **Objective**

The objective of the training course is to give the participants increased knowledge about how to contribute to the development of communication in people who are congenitally deafblind.

One of the underlying principles proposed in the approach is the principle of diagnostic education, which implies that the pedagogic practice is explorative. Knowledge of how normal communication development takes place will be combined with experience of how congenitally deafblind persons are likely to establish and develop communication skills.

A model of development which can be used as a tool for the analysis will be presented. The model will be presented and used in practice by analysing the video tapes of the participants, and suggestions for further intervention will be discussed.

Relevance to the participants' working situation is secured through video based analysis of their cases.

### **Speakers**

Anne Nafstad, Psychologist at Skådalen Resources Centre in Oslo

Inger Rødbroe, Coordinator of the Deafblind Department at Aalborgskolen

Jacques Souriau, Director of Resource Centre for Deafblind People in France

### **Venue**

Nordic Staff Training Centre for Deafblind Services (NUD), Dronninglund Castle, Denmark

### **Date**

17 – 23 June 2000

### **Course Fee**

DKK 5 580 covers full board and all course activities. Application Closing Date 17 January 2000.

### **Travel and Accommodation**

The participants will arrange and cover the costs of their travel to Dronninglund. Accommodation costs are included in the course fee, and will be at the Dronninglund Castle, where the course also takes place.

### **Language Interpretation**

The working language is English. The NUD can provide facilities for simultaneous interpretation for participants with insufficient command of English who wish to bring their own interpreters.

### **Applications for Participation**

For further information or to receive an application form contact:

The Nordic Staff Training Centre  
for Deafblind Services (NUD)  
Slotsgade 8  
DK-9330 Dronninglund  
Denmark

Phone: +45 96 47 16 00

Fax: +45 96 47 16 16

E-mail: nud@nud.dk

### **'Co-Creating Communication'**

**written by Anne Nafstad and Inger Rødbroe**

For copies of this book which outlines perspectives on diagnostic education for individuals who are congenitally deafblind and individuals whose impairments may have similar effects, please contact:

Forlaget Nord-Press  
Nr. Ringgade 2  
DK-9330 Dronninglund  
Denmark

Phone: +45 98 84 10 20

Fax: +45 98 84 24 88

E-mail: basistryk@email.dk

Internet: www.basistryk.dk

Cost: DKK 134,00 (inc VAT)





THE AUSTRALIAN DEAFBLIND COUNCIL

## THE 5<sup>TH</sup> NATIONAL DEAFBLIND CONFERENCE

# DEAFBLINDNESS: KEEPING IN TOUCH BEYOND 2000

7 – 10 APRIL 2000

• ESPLANADE HOTEL  
FREMANTLE

If you have any queries about the program, please contact:

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### Venue

Conference and functions will all be held at the Esplanade Hotel, Fremantle, Western Australia.

### Date

7–10 April 2000

### Registration Fees

Full registration including 2 day conference with morning and afternoon teas, lunch and Friday evening cocktail party.

### Cost

- Aus\$320.00
- Registrations received prior to 7 February 2000: Aus\$288.00
- Deafblind individuals: Aus\$100.00
- Students of recognised educational institution: Aus\$160.00
- Parent/Carer of a deafblind person (excluding professional service providers): Aus\$215.00

For general registration enquires, or for information about day registration fees and the cost of optional extras please contact:

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### Theme

This is a conference for people who are deafblind, their friends, families, service providers and any others interested in extending their networks and knowledge of deafblindness.

### Keynote Speakers

*Graham Hicks*  
deafblind himself, lives in England and works for Sense.

*Dr George L Williams*  
neonatal paediatrician based at the New Children's Hospital, Westmead, NSW.

### Conference Program

This includes workshops, panel discussions, opportunities for networking and a range of national and international speakers including Sharon Barrey Grassick WADBA and Dr Mike Steer, Renwick College NSW as well as presenters from Singapore, New Zealand and Sweden.





The General Assembly ratified the above reported to the Management Committee and the Council and also formally ratified the new Constitution of DbI. Furthermore, the General Assembly adopted the following resolution:

*“Deafblind International calls on national governments throughout the world, when considering definitions of disability and descriptions of the categories of disability, to specifically recognise deafblindness. Deafblindness means a combination of visual and hearing impairment. Such recognition must be written into legislation – and should refer to the particular needs of deafblind people, which are different from the needs of people with a single sensory impairment.”*

## Other news from the Council and Management meetings

The **13th World Conference** in 2003 is to be hosted by the Canadian Deafblind and Rubella Association, in the Delta Meadowvale Resort and Conference Centre, Mississauga, near Toronto, Canada. The proposed dates were announced as Tuesday 5th August – Sunday 10th August 2003.

The details of the **first DbI Asian Conference** in Ahmedabad, India were also discussed. The dates were announced as 11 – 12th February 2000. The conference will be hosted by the Blind People's Association and is being jointly sponsored by Sense International and Hilton/Perkins Program.

The **DbI European Conference** in 2001 is to be held at the Leeuwenhorst Centre in Noordwijkerhout, the Netherlands and is being hosted by a consortium of

six organisations. The dates were announced as 24 – 29 July 2001.

An **International Networks Manager** for DbI has been successfully appointed. Natasha Cox is currently working in Brussels for an international network called Education International. She has much international experience, including international networks, transnational projects and European Union funding. She will take up her position in February.

DbI is a vital network for all involved in the field of deafblindness. In order to best serve our members, it is crucial that we raise sufficient funds through fees to finance our basic activities. With this in mind, there is a Corporate as well as an Individual membership form for you to fill in. Please encourage as many people as possible to join.

**Non-Voting Members** consist of individuals, national networks and non-subscribing Corporates. Non-voting members can contribute to the decision making process of DbI through either a corporate member or an international network. Non-voting members will receive a copy of DbI Review and other relevant DbI information. Non-voting membership is free, but an annual donation of US\$30 is requested to cover costs.

**Voting Members** are the representatives of **corporate members** who have paid their subscription fees, and the representatives of recognised DbI networks.

There are now two tiers of **Corporate Membership:**

*Large Corporates:*

Annual Fees between US\$3,000 and US\$5,000

*Small Corporates:*

Annual Fees between US\$300 and US\$1,500

Corporate Members can be nominated to sit on the Council.

## Correction

In the last edition of DbI Review we published an article by Patricia Pastor entitled “Engineering in Cardboard”. This article did not acknowledge the authorship and support of Alex Truesdell. This was an error on our part and we apologise for the embarrassment it has caused.









# DbI

## DEAFBLIND INTERNATIONAL

### The World Association Promoting Services for Deafblind People

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Marjaana Suosalmi, *Service Foundation for the Deaf*

### DbI Review Editor:

Eileen Boothroyd, *Sense*

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William Green, Vice-President DbI - *Lega del Filo d'Oro*  
Rodney Clark, Secretary, DbI - *Sense*

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Marjaana Suosalmi, Strategic Planning Officer DbI - *Service Foundation for the Deaf*

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Bernadette Kappen - *Overbrook School*

Anny Koppen - *Nordic Staff Training Centre For Deafblind Services*

## Networks

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