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AUGUST 2014

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Monthly Support Groups

Heads Up Group

Contact Dave Munroe at SCIL:
(217)523-2587 v/tty

Stroke/Brain Injury Support Group

Contact Lisa Cline at: (217)788-3461 or email:
cline.lisa@mhsil.com

Personal Assistant Employers Group

Contact Bradley Kinney at SCIL:
(217)523-2587 v/tty

Post-Polio Group

Contact Bradley Kinney at SCIL:
(217)523-2587 v/tty

WREN (Women's Resource Empowerment Network)

Contact Susanne Cooper at SCIL:
(217)523-2587 v/tty

BEST (Becoming Empowered and Successful Teens) and Parent Transition Support Group

Contact Carolyn Thorpe at SCIL:
(217)523-2587 v/tty

Lincolnland Stroke Support Network

Contact SCIL for more information.
(217)523-2587 v/tty



Having trouble hearing on the telephone?
Illinois has a **FREE** amplified phone program!
Call us or stop by:
SPRINGFIELD CENTER FOR INDEPENDENT LIVING
330 South Grand Avenue West
Springfield, IL 62704
217-523-2587
Monday-Friday 8:30 A.M.-5:00 P.M.
www.itactty.org A FREE program required and governed by Illinois law.



SCIL SPRINGFIELD CENTER FOR
Independent Living

August 2014

THE SCIL ADVOCATE

"Increasing opportunities for persons with disabilities through advocacy, services, and public education."

Accessible Healthcare Workshop Held

Nineteen individuals attended an accessible healthcare workshop held on June 26, 2014 at SCIL. Andrés J. Gallegos, Esq., a disability rights attorney with the law firm of Robbins, Salomon and Patt, Ltd. in Chicago, provided a two and a half hour presentation on accessible healthcare.

We have received many positive comments on the June workshop

and several individuals have expressed an interest to hear Andrés speak again. We asked Andrés if he would provide us with an article for our next newsletter, and he was very happy to satisfy that request. We hope we can schedule Andrés to return to Springfield for another presentation, but until then, please enjoy his very informative article below.

Patient Advocacy: The Key to Accessible Healthcare

By Andrés J. Gallegos, Esq.

For several days, John had a severe toothache that was getting worse each passing day. The throbbing pain was affecting his ability to speak, he could not chew his food, and he had difficulty sleeping. His family called the dentist in the town where he lived to get John an emergency appointment. The dentist told the family that he could not treat John because John uses a wheelchair and there was no way to transfer him onto the examination chair. John's family called other dentists in town and each told John's family different reasons why they could not treat him – there were stairs leading to the main entrance, the examination room was too small to

fit his wheelchair, or he could not be treated unless he transferred to the exam chair. John's family called every dentist in town and in nearby towns, each of them offered reasons – which were now all too familiar to John's family – as to why they could not treat John. One month after John's family called the first dentist, John was treated at a dental clinic 2.5 hours from his house. Because there was a delay in getting treatment, John required oral surgery because the tooth was now abscessed.

For persons with disabilities, John's story is their story, and it's an all too familiar story. All persons with disabilities have multiple stories like John's, involving dentists, primary

(Continued on page 2)

TABLE OF CONTENTS

PACER Launches National Parent Center on Transition and Employment	4
10th Annual Illinois Statewide Transition Conference	4
Five Complete Spring Legislative Training Program	5
Volunteer Celebration Held at SCIL	5
Fall Legislative Training Program	5
SERTOMA Hearing Aid Recycling Program	6
INNOCAPTION Free Captioning for smartphones	6
Hard of Hearing Awareness	7
Monthly Support Groups	8

(Continued from page 1)

care doctors, gynecologists, optometrists and others. It has been 24 years since the enactment of the Americans with Disabilities Act (ADA), and persons with disabilities still receive less than equal treatment when it comes to healthcare. It has also been nearly 10 years since the Surgeon General of the United States issued a Call to Action to Improve the Health and Wellness of Persons with Disabilities in order "to promote accessible, comprehensive healthcare that enables persons with disabilities to have a full life in the community with integrated services..."¹ In his report, the Surgeon General highlighted the problems, such as:

Persons who are blind are not offered or provided treatment or wellness information in accessible formats;

- Persons who are deaf are not provided sign language interpreters or video remote interpreting (VRI) and no procedures exist to have sign language interpretive services or VRI readily available for deaf patients;
- Examination rooms are too small or are cluttered with furniture, precluding persons with mobility impairments who rely upon the use of wheelchairs to freely maneuver their wheelchairs inside those examination rooms;
- Examination tables do not lower to facilitate the persons with mobility impairments who rely upon the use of wheelchairs to independently transfer from their wheelchairs onto the examination tables;
- No safe means are provided to lift persons with mobility impairments who rely upon the use of wheelchairs from their wheelchairs onto examination tables, such as portable lift systems or fixed overhead lift systems; and
- Weight scales are not accessible for persons with mobility impairments who rely upon the use of wheelchairs.

¹<http://www.surgeongeneral.gov/library/disabilities/calltoaction/index.html>.

Although there is federal law mandating accessibility, and urging from the U.S. Surgeon General, access to healthcare without barriers will not be achieved until persons with disabilities insist upon it and become better advocates. While it may be difficult to accept, for the past 24 years, persons with disabilities have aided and abetted their doctors, dentists, optometrists and other healthcare

providers, from not having to comply with the ADA. We have done so by, among other things, agreeing to be examined in our wheelchairs, allowing nurses to guess our weight or use an old weight recorded in our medical records, and by bringing family or friends to our appointments to help us while we're there. We have aided and abetted by keeping silent about our experiences at our doctor's office, or complaining about problems there, but only to our family and friends.

Hospitals, doctors' offices, dental clinics, eye care clinics are all "places of public accommodation" and have a general obligation, under Title III of the ADA, to ensure that individuals with disabilities have full and equal access to all of their services. It is discriminatory to deny persons with disabilities the equal opportunity to participate in a service and to provide services in a way that does not provide an equal benefit. Healthcare providers have specific obligations under the ADA to, except within narrowly tailored limits: modify and remove architectural barriers; modify policies, practices, or procedures to avoid discrimination; provide auxiliary aids and services when necessary; and ensure that no persons with disabilities are excluded, denied services, segregated or otherwise treated differently from other individuals because of the absence of auxiliary aids and services.

Persons with disabilities and their family members need to become better advocates. When it comes to healthcare, advocacy is strengthened if viewed in three stages – Pre-Appointment, During the Appointment, and Post-Appointment (PDP).

- **Pre-Appointment.** Becoming a better healthcare advocate starts in the Pre-Appointment stage. This is where the person with a disability becomes informed and knowledgeable by researching the doctor, the facility where the exam or procedure will occur, and the specific procedure that is needed, all of which can be obtained on the internet. Here is where the person with a disability identifies the specific accommodation that he or she will need so that the specific accommodation can be requested when the appointment is made. Persons with disabilities should also consider requesting a pre-appointment visit to the clinic, hospital, facility, office, etc., to meet the doctor and his staff, and to familiarize themselves with the clinic, hospital, facility, office, etc., and to see for themselves how accessible it really is. When making the appointment, identify yourself as a person with a disability, be very specific about the assistance and the accommodations you will

Hard of Hearing Awareness

From the Hearing Loss Association of America

Basic Facts About Hearing Loss

Statistics

- About 20 percent of adults in the United States, 48 million, report some degree of hearing loss.
- At age 65, one out of three people has a hearing loss.
- 60 percent of the people with hearing loss are either in the work force or in educational settings.
- While people in the workplace with the mildest hearing losses show little or no drop in income compared to their normal hearing peers, as the hearing loss increases, so does the reduction in compensation.
- About 2-3 of every 1,000 children are hard of hearing or deaf
- Estimated that 30 school children per 1,000 have a hearing loss.

Statistics sources: [John Hopkins Medicine](#)

Other sources: [National Information Center on Deafness and Other Communication Disorders](#), [National Institutes of Health](#), [National Council on Aging](#), and the [MarkeTrak VIII Study](#) by Sergei Kochkin, Ph.D.

Tips for Hearing Person to Communicate with Person who has a Hearing Loss

Set Your Stage

- Face person directly.
- Spotlight your face (no backlighting).
- Avoid noisy backgrounds.
- Get attention first.
- Ask how you can facilitate communication.
- When audio and acoustics are poor, emphasize the visual.

Get the Point Across

- Don't shout.
- Speak clearly, at moderate pace, not over-emphasizing words.
- Don't hide your mouth, chew food, gum, or smoke while talking.
- Re-phrase if you are not understood.

- Use facial expressions, gestures.
- Give clues when changing subjects or say "new subject."

Establish Empathy with Your Audience

- Be patient if response seems slow.
- Talk to a hard of hearing person, not about him or her to another person.
- Show respect to help build confidence and have a constructive conversation.
- Maintain a sense of humor, stay positive and relaxed.

Tips for the Person with Hearing Loss to Communicate with Hearing People

Set Your Stage

- Tell others how best to talk to you.
- Pick your best spot (light, quiet area, close to speaker).
- Anticipate difficult situations, plan how to minimize them.

Do Your Part

- Pay attention.
- Concentrate on speaker.
- Look for visual clues.
- Ask for written cues if needed.
- Don't interrupt. Let conversation flow to fill in the blanks and gain more meaning.
- Maintain a sense of humor, stay positive and relaxed.

Establish Empathy with Audience

- React. Let the speaker know how well he or she is conveying the information.
- Don't bluff. Admit it when you don't understand.
- If too tired to concentrate, ask for discussion later.
- Thank the speaker for trying.



7910 Woodmont Ave., Suite 1200
Bethesda, MD 20814
phone: 301.657.2248
<http://www.hearingloss.org>

SERTOMA Hearing Aid Recycling Program

The SERTOMA Club of Springfield, Illinois established the SHARP program in 1990. SHARP stands for SERTOMA Hearing Aid Recycling Program. The purpose of the program is to help individuals who need hearing aids but cannot afford them. Senior citizens and low income individuals are the primary recipients.

Hearing aids can be donated to the SERTOMA Club by calling 217-529-0341, or bring them to The Hearing Center at 644 N Second, in Springfield. The donated hearing aids are stored at The Hearing Center, which is an affiliate of Memorial Medical Center.

The SERTOMA Club receives referrals from many sources, including the Senior Services Center of Central Illinois, doctors' offices, Department on Aging, churches, visiting nurses, and self-referrals. The application process is easy:

1. Applicants fill out and submit a simple one page application itemizing their ongoing expenses and provide a copy of a document supporting their income (copy of 1040 tax return or VA/Social Security statement). Note that generally people on Medicaid are eligible for hearing aids – but individuals on Medicaid should check their status first before applying.
2. The SHARP committee reviews and approves

the application, an approval letter is sent to the applicant, and a copy is forwarded to The Hearing Center.

3. The Hearing Center contacts the applicant to schedule an appointment for an audiological exam, evaluation for the most appropriate type of aid/aids for the individual, and if necessary, a wax ear mold.
4. The Hearing Center selects a used hearing aid from their stock and sends it to a repair laboratory to be refurbished to a like-new condition meeting the applicant's specifications.
5. About two weeks later, the recipient is contacted to return to The Hearing Center for the final fitting, adjustment, and instructions on the care of the hearing aid. At this time, the recipient is requested to remit \$250, which is the cost of the audiological exam and the lab's refurbishing fees.

The Sertoma Club does not have an ongoing role with the recipient once the hearing aid is received. The recipient will work directly with The Hearing Center after placement to resolve any issues that may arise.

Contact The SERTOMA Club with questions about the hearing aid program by calling Joan at: **217-529-0341**. The mailing address for the Sertoma Club: **Springfield Sertoma Club
PO Box 2471
Springfield, IL 62705-2491.**

InnoCaption – Free Service for deaf or hard of hearing

What is InnoCaption Service?

InnoCaption provides free real-time caption service for the deaf and HOH (Hard of Hearing) mobile user. It will function with any smart phone that utilize the Android or iPhone OS. InnoCaption app is turned on whenever an inbound call is delivered and automatically turned off once the call is terminated by either party. This gives the caption user peace of mind that they can give their caption number out to anyone with no fear of a complicated process to follow by either party. In addition our product will work on any 4G or WiFi network with the same level of performance. Regardless of your network provider, the free real-time caption service will be provided by InnoCaption.

*** Registration is required to use InnoCaption service and it is free.**

-- InnoCaption is a free service for those with qualified hearing loss.

-- Paid for by the federal government through

the FCC TRS Fund.

*** 4G LTE network is required for Verizon and Sprint network users.**

* Voice and Data Plan is required to use InnoCaption Service. **Important Note:** InnoCaption requires Simultaneous Voice & Data through your mobile network provider on your smartphone. To receive this service, **make sure your smartphone supports simultaneous voice and data on your mobile network carrier.** Ask your mobile service provider.

[Go to the website http://www.innocaption.com](http://www.innocaption.com) to see the requirements and user interface for InnoCaption service, or to download a professional certification form.

Recent FCC regulations require all captioned telephone users to submit a certification from their hearing care professional certifying their hearing loss.

You may email questions to:

support@innocaption.com

need for the appointment. If you think you'll need a bit more time for the visit, ask for it.

- **During the Appointment.** This stage requires the careful balancing of advocating, but foremost, getting the care that you need. In this stage, upon arrival, confirm that the specific accommodation you requested is in fact there for you to use. Do not wait until you are in the exam or procedure room to check. If the accommodation you requested is not there, then insist upon it being made available or consider rescheduling the appointment for a date and time when it will be available. If you determine you still want to go forward with the exam, procedure or visit even though the requested accommodation is not there, tell the doctor, nurse and his staff that "for this visit" you'll agree to go forward without the requested accommodation, but that you insist it be present for the next visit or appointment. Insist that the absence of the requested accommodation be recorded in your medical record for that visit. Communicate with your doctor, nurses and staff. Ask questions. Give them constructive feedback about what is going right and wrong with the visit. During the visit, avoid the temptation to enable the doctor or his staff. What this means is that although you may have brought a family member or friend to the appointment, allow the doctor, nurse or his staff to help you as needed. If we keep having friends and family help, the doctors, nurses and staff will not learn how and never offer to help. This also means if you are asked for your weight, insist you be weighed. Before leaving the hospital, clinic or facility, be sure that you have contact information (that is, mailing address, email address, and telephone number) for the doctor, the manager or director of patient relations, the ADA director (if there is one), and of anyone else at the hospital, clinic or facility who handles patient complaints.

- **Post-Appointment.** As soon as possible after the appointment provide the doctor, nurse and staff written feedback about what went right and what went wrong during the appointment. The feedback should be as specific as possible identifying what occurred, how it impacted you, and what you would like to happen the next time. For example: "the lift equipment that I requested three weeks in advance of my appointment was not provided. Reluctantly, I agreed to be manually lifted onto the examination table for the appointment. I was greatly concerned that I was going to be dropped or injured. I ask that you ensure that for my next appointment lift

equipment will be available, and that you or your staff call me to confirm that it will be available." Regardless of whether the feedback is praise and gratitude, or criticism, copy the manager or director of patient relations, the ADA director (if there is one), and anyone else at the hospital, clinic or facility who handles patient complaints. If there was a problem and you believe your rights were not respected you should inform your Center for Independent Living and they can guide you in taking action, whether that is filing a complaint with the Illinois Human Rights Commission, Illinois Attorney General, the US Department of Justice or connecting you with disability rights attorneys.

The laws exist. We have the ability to make healthcare truly accessible in our communities, and it starts by each of us becoming better advocates. All of us are stronger when one of us stands up.

Andrés J. Gallegos, Esq., is a disability rights attorney with the law firm of Robbins, Salomon and Patt, Ltd. in Chicago, and has been living with the effects of a spinal cord injury for the past 17 years. Andrés may be reached at (312) 456-0381 or via email at agallegos@rsplaw.com.

12th Annual CONFERENCE FOR CAREGIVERS

For Caregivers of Older Family Members and Friends and Grandparents and Other Relatives Caring for the Next Generation

Saturday, September 6, 2014

8 a.m. to 2:30 p.m.

Northfield Inn, Suites & Conference Center

3280 Northfield Drive, Springfield, Illinois

*Presented by Area Agency on Aging
for Lincolnland*

Conference participants will attend a variety of interesting and educational breakout sessions. Attendees will also have an opportunity to learn about helpful services and products in the exhibit hall. Lunch will be provided and will be followed by luncheon speaker Dr. Carolyn Peck, Associate Professor, Department Chair, Human Services – Gerontology, University of Illinois at Springfield. A registration fee of \$20.00 must be mailed with the registration form. This fee will be refunded to attendees at the conference. Call 217-787-9234 for more information and a registration form.

PACER Launches National Parent Center on Transition and Employment

For families of youth with disabilities, the transition from high school to employment, postsecondary education, and life in the community presents a variety of challenges. PACER is launching the National Parent Center on Transition and Employment to support families, youth, educators and employers as they help teens and young adults with disabilities reach their goals into adulthood.

PACER's Technical Assistance on Transition and the Rehabilitation Act (TATRA) Project and other Parent Information and Training programs funded by the US Department of Education, Rehabilitation Services Administration (RSA) focus on helping families prepare youth with disabilities for employment and independent living. Projects provide information and training on transition planning, the adult service system, and strategies that prepare youth for successful employment, postsecondary education, and independent living outcomes.

Current vocational rehabilitation policy emphasizes the preferences of individuals with disabilities and recognizes the importance of family expertise.

Because they know their family member's strengths, families help make critical contributions to employment. In addition, parents often provide critical supports for their sons and daughters with disabilities long after they reach adulthood.

The center will offer innovative tools, reliable research, and interactive training to address families needs in ways that parents and children can easily use. Youth with disabilities often lack knowledge of where to start in planning a goal-setting process. Parents are in a similar situation – most have high expectations for their youth but lack specific information on how to help with the transition and become college and career-ready after high school.

For more information, go to <http://www.pacer.org/tatra/rsa.asp>

The **BEST (Becoming Empowered and Successful Teens) and Parent Transition Support Group** will resume in September. Call Carolyn Thorpe, Youth Transition Specialist at: (217)523-2587 v/tty for more information.



10th Annual Illinois Statewide Transition Conference October 27-28, 2014 The Crowne Plaza Hotel & Conference Center Springfield, Illinois

The 10th Annual Transition Conference for high school aged students and young adults with disabilities, their family members and teachers, vocational professionals, caregivers, health care professionals, college students pursuing careers in special education and community advocates will be held at The Crowne Plaza Hotel and Conference Center in Springfield, Illinois from October 27-28, 2014.

The conference, titled "Stepping Stones of Transition", invites participants to imagine the possibilities for students with disabilities in the areas of independent living, education and training, employment, community integration, health care, and self-advocacy.

Conference sessions will be organized into 4 tracks: Education, Employment, Community and Healthcare.

To read more about keynote speakers, breakout sessions, and plenary sessions go to <http://www.illinoistransitionconference.org/#registration>. Space is limited and breakout sessions have limited capacity on a first come basis. So register early to ensure admission to your top choice sessions. Registration deadline is September 30th.

For more information contact the conference organizers via email at info@illinoistransitionconference.org. A limited number of hard copy registration booklets will be made available by request only to help those who do not have Internet access get registered. Contact Family Matters at 866-436-7842.

Five Complete Spring Legislative Training Program

The Spring 2014 Legislative Training class consisted of 7 sessions. Topics included: an introduction to advocacy, an introduction to government, and advice for meeting with legislators. The participants also attended the CCDI Annual meeting and conference which included a rally at the State Capital. During the rally and visit, participants located their legislators to discuss issues important to people with disabilities.

The training topics were presented through lectures, group discussions, guest speakers, videos, and group activities. On July 18th, the five individuals who completed the program attended a celebration ceremony and were given certificates of completion.



Back row (left to right): Emil Mazzini, Andre Griffin, Earl "Mike" Reese, and Marla Neal.

Front row (left to right): Melissa Norman, Deb Gerstenberger

Volunteer Celebration Held at SCIL

The Annual Volunteer Celebration was held at SCIL on June 12, 2014 from 1:00 – 3:00 pm. Each volunteer received a certificate of appreciation, a gift and lunch!

Every year SCIL honors the volunteers who graciously donate their time to work at SCIL on an as-needed basis. Volunteers label materials for bulk mailings, answer the telephone, and assist with other projects to free up time for SCIL staff to focus on consumer needs.

If you would like to volunteer at SCIL, please contact Kathy Paul, Volunteer Coordinator.



Left to right: Belinda Duncan, Malioka Davis, Toby Basil, and Kathleen Lott. Not present for the picture: Damilola Ajibola, Melinda McDonald, Zachery Khan, and Shane Pastrovich



Fall Legislative Training Program

*Are You a Person with a Disability?
Do You Want Your Voice to Be Heard?*

Springfield Center for Independent Living will hold an informational meeting about the next

Legislative Training Program

1-3 PM, Wednesday, October 22,

Please join us at the SCIL office to learn more about this exciting program. For more information or to reserve a spot, please contact

Melissa Norman (217) 523-2587 v/tty

Please contact us a minimum of two weeks prior to the meeting if you need accommodations.