New Tele-Support Group For Parents of Children with Albinism

The Guild’s tele-support program recently added a new group to provide support for parents of children with albinism. The group was formed in partnership with the National Organization for Albinism and Hypopigmentation (NOAH).

Our tele-support groups meet on a weekly basis. They offer support to parents of children with Retinopathy of Prematurity (ROP), Cortical Visual Impairment, Leber Congenital Amaurosis, Hermansky Pudlak Syndrome, Autism Spectrum Disorders and Visual Impairment, Achromatopsia, CHARGE Syndrome, and other disorders. There is a group for legally blind teenagers planning to attend college and a group for sighted siblings.

Albinism

The latest group is facilitated by Sheila Adamo, LCSW. Ms. Adamo is not only a Social Worker, but also the parent of a teenage son with albinism. “I’m excited about the opportunity to interact with young parents whose child has recently been diagnosed with albinism”, said Ms. Adamo. “I wish such a group had been available to me when my child was diagnosed.”

Albinism refers to both Oculocutaneous Albinism (OCA) as well as Ocular Albinism (OA). People with OCA have little or no pigment in their eyes, skin, or hair. OA is much less common and primarily involves the eyes, while skin and hair color appear normal.

All forms of albinism are associated with vision problems, such as reduced sharpness; rapid, involuntary eye movements (nystagmus); and increased sensitivity to light (photophobia). The degree of vision impairment varies and many people with albinism are “legally blind”.

While the majority of children with albinism live normal life spans and have the same types of medical problems as the rest of the population they can be subject to social isolation and stigmatization.

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When the parents have normal hair and eye color for their ethnic backgrounds and their child does not, that compounds the child’s sense of being different. These are some of the issues that the Guild’s new tele-support group will address with parents.

Participating in a Support Group

Our support groups connect parents of children with the same eye conditions, which allows families to share resources, experiences, strength and hope. Maria Ceferatti, mother of 12-year old Simon, recently described her participation in the Retinopathy of Prematurity tele-support group and why it is so important to her.

“I joined the phone group when Simon was very little. I spoke to other people who were dealing with things on a day-to-day basis and they made their situation sound normal, which was helpful because we would take Simon to the playground and there was no sitting and watching him play. I was standing under the jungle gym, helping him climb, hoping he didn’t fall and break his neck. And to hear other moms say they’re doing the same, made me think ‘Oh gosh, I’m not the only one out there. I may be the only one in my neighborhood, but I’m not the only one out there.’ And that gives a parent such peace of mind, and that’s what the phone group offered then and still does.”

For more information on the Albinism support group or any of the Guild’s other telephone support groups contact Dan Callahan, Director of the Guild’s Children’s Vision Health program at 212-769-7815.

Maria Ceferatti and her son Simon. She is a member of the Retinopathy of Prematurity tele-support group.
The Guild Sees *Lucky Guy* on Broadway

The Guild’s supporters recently gathered for an evening on Broadway at one of the most anticipated theatrical events of the season, *Lucky Guy*, at the Broadhurst Theatre. Nora Ephron’s last major work, about the New York journalist Mike McAlary, starred Tom Hanks in his Tony-nominated Broadway debut. The theatre benefit, which was a great success, started with a dinner at the nearby Marriott Marquis Hotel. The event was co-chaired by Pauline Raiff, Jane Rittmaster and Susan Mendik Tarkinow.

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**WANDA FIGUEROA-KILROY APPOINTED TO ADVISORY GROUP**

GuildNet’s Executive Vice President, Wanda Figueroa-Kilroy, RN, MSN, has been appointed by the New York State Department of Health to the Home and Community-Based Care Work Group, an advisory group to the State. The group will examine and make recommendations on the following issues: State and Federal regulations and policy guidelines; Efficient home and community-based care delivery; Alignment of functions between managed care entities and home and community-based providers. The New York State Commissioner of Health will chair the advisory group, which will issue its report, with recommendations, in March 2014.

GuildNet’s health plans serve 14,000 members in New York City’s five boroughs as well as in Nassau, Suffolk and Westchester Counties.
Nationally Recognized Programs Train Professionals to Meet the Needs of People with Vision Loss

The Guild’s nationally recognized training initiatives prepare healthcare professionals in all settings to identify and meet the specialized needs of their clients with vision loss. The availability and reach of our programs are growing each year.

Online Continuing Education

The 2nd edition of our online program, Low Vision in Older Adults: Foundations for Rehabilitation was launched at the American Occupational Therapy Association (AOTA) Annual Conference in April. Produced in collaboration with AOTA, the course trains occupational therapists (OTs) in low vision causes, effects and interventions, with an emphasis on optical considerations and strategies for environmental adaptation and occupational performance.

The updated content reflects advances in the field and the expanding role of OTs in providing low vision rehabilitation. It also includes a new module on evaluating client difficulties with daily activities because of vision loss.

There are over 100,000 OTs in the United States. They are treating an increasing number of clients with low vision, due to our aging population. A growing number of OTs are seeking to specialize in low vision rehabilitation, or at a minimum be able to effectively identify and address the needs of their clients with vision loss. Our low vision course provides seven hours of continuing education credit through AOTA and is available through www.aota.org.

Healthy Nutrition

We completed the 5th session in our series of afterschool programs in partnership with the West Roxbury YMCA. The programs, held at 11 afterschool sites, were led by a Registered Dietitian for over 250 children, ages 6-12. The focus was on building a healthy breakfast, while reinforcing previous concepts of food-as-fuel, reducing sugar intake, eating mindfully, reading labels, and balancing each meal, in order to control weight and prevent diabetes.
Low Vision Rehabilitation

For years we have provided training for healthcare professionals in the skills needed to identify and address vision impairment in the clients they treat at home. Recently we completed training occupational therapists (OTs), physical therapists (PTs), and speech language pathologists at Visiting Nurse Services in Westchester (VNSW). In five workshops, they learned to conduct a basic vision assessment, to incorporate basic low vision devices into therapy, and to integrate adaptive devices and techniques into treatment.

This training is part of a broad educational initiative with VNSW in which all of the agency’s nurses, social workers and home health aides are receiving education and training in caring for people with vision loss.

Mobility and Communication Skills

For some time we have been offering training sessions to staff from group homes throughout New York City. One such group recently completed a workshop where they learned basic skills for improving interactions with their clients with vision loss. In an interactive workshop, participants used vision simulators to experience how common vision conditions can affect the way a person functions. They also practiced basic mobility techniques such as Trailing and the Guide Technique for walking safely with a visually impaired or blind resident. Ways to create a safe environment were also demonstrated.

Students from UAB

A University of Alabama at Birmingham (UAB) graduate student in Occupational Therapy (OT), Swetal Thaker (right) is completing a three month Level II Fieldwork Placement in the Guild School. Lillian Lim (left), a practicing OT from Singapore, is enrolled in UAB’s Graduate Certificate in Low Vision Rehabilitation. She visited us for a week to observe therapists in a variety of programs. They are shown here with Guild OT Yu-Pin Hsu (center), who has an Advanced Certificate in Low Vision from UAB.
GUIDL/ARVO OBERDORFER AWARD SYMPOSIUM

Gregg Vanderheiden, PhD, received the second Oberdorfer Award in Low Vision at the 2013 Annual Meeting of The Association for Research in Vision and Ophthalmology (ARVO) in Seattle. To celebrate the occasion, ARVO’s Low Vision Group organized a symposium entitled “Beyond Large Print: Advances in Accessibility and Technology for the Visually Impaired”.

Dr. Vanderheiden, Director of the Trace Research and Development Center in the College of Engineering, University of Wisconsin-Madison, presented “Using the Cloud and Emerging Technologies to Provide On-Demand Low Vision Solutions Anytime, Anywhere, on Any Device”.

The symposium’s other presenters were:

- Aries Arditi, PhD, Principal Scientist, Visibility Metrics LLC: “Accessibility and Vision Rehabilitation Science: Tear Down That Wall!”
- James Coughlan, PhD, Senior Scientist, Smith-Kettlewell Eye Research Institute: “Computer Vision-Based Assistive Technology for the Visually Impaired”
- Peter Hallinan, PhD, Chief Strategy Officer, The Blindsight Corporation: “Using Text Detection to Help Low-Vision Users”

The Oberdorfer Award was created by the Guild in collaboration with the ARVO Foundation for Eye Research because of our special interest in low vision research and rehabilitation. Michael D. Oberdorfer, PhD, after whom the award is named, served for many years at the National Institute of Health’s National Eye Institute as Director of the Low Vision and Blindness Rehabilitation program.

Guild Joins Westchester Equal Access

The Guild and its programs GuildNet, GuildCare and Adaptive Technology, joined community groups and businesses in the Westchester Equal Access Campaign, launched by the Westchester Independent Living Center at the Yonkers Riverfront Library. The event was followed by a workshop on the subject of Equal Access: “Busting through Barriers – a primer on ADA regulations and what it means to your business.”

Joe Bravo, Executive Director of the Westchester Independent Living Center, explained the importance of the campaign, “This is a great opportunity to improve access to businesses in Westchester County for all disabled people. Access allows people with disabilities to participate fully in their community.”

Guild President and CEO Alan R. Morse said of the campaign, “We’re pleased to be part of this new initiative. The Guild’s roots in Westchester date back to 1914, when we made our commitment to help people with vision loss live with independence and dignity. The programs we now offer in Westchester – GuildNet, GuildCare and Adaptive Technology training are all aimed at fulfilling that pledge.”
The Guild Celebrates Its Volunteers

In April, we recognized our volunteers and student interns. The theme was “Volunteers: Touching Lives, Lifting Spirits”.

Volunteers gathered at the Guild’s City Center where Mayya Etis, Manager of Volunteers and Interns was host. Melissa Farber, Vice President, Human Resources, spoke of the importance of volunteers to the Guild. Philip Rosenthal, Guild COO, spoke to the volunteers about how important they are and described the highlights of the past year.

Among volunteers given length of service awards, Rita Rosenberg was singled out by New York City Council Member Gale A. Brewer’s office with a Proclamation paying tribute to her as a long-time Guild volunteer and celebrating her 100th birthday.
Students Help Develop Tactile Watch

The Boston-based company Eone recently visited the Guild’s Academic Rehabilitation program students and staff with its newly built watch prototype – The Bradley Timepiece. In 2012, Eone’s Hyungsoo Kim asked for Guild student and staff feedback on a concept prototype for the tactile watch. Normally with a tactile watch, the user touches either the watch “hands” or Braille “dots”. With The Bradley Timepiece, the user gently touches two ballbearings, which travel around the face of the watch much like conventional “hands”. One locates hours, the other minutes.

STUDENTS FROM BARNARD’S PRE-COLLEGE PROGRAM VISIT THE GUILD

High School juniors and seniors who are members of the Barnard College Pre-College Program and who have an enthusiasm for the sciences, visited the Guild in late June. The topic of their visit was how vision loss affects the learning process.

GuildCare Members Enjoy Zumba!

Members of our Adult Day Health Care (ADHC) program participated in National Senior Health & Fitness Day in late May. Activities were offered that emphasized vision health, blood pressure screenings and health care discussions. The highlight of the day for everyone was the fitness exercise routine which included ‘Zumba’, specially designed for seniors and for people with disabilities, set to rhythmic Latin music.

GuildCare is New York State’s only ADHC provider specializing in services to persons with vision impairment and chronic medical conditions, such as diabetes, high blood pressure or a history of stroke, heart disease or eye disease. GuildCare first opened in Yonkers in 1984, and now serves adults in Albany, Buffalo, Manhattan and Niagara Falls.
Graduation Day

The Harriet and Robert Heilbrunn School at the Guild held its annual graduation exercises in late June. This year’s graduate was Daquan Boyce White, who has been a student at the school for 13 years. The ceremony was held in the Guild’s City Center auditorium and was attended by Guild School students, their teachers, families and friends.

After music and dance presentations, achievement certificates were awarded to students in celebration of the progress made during the year in subjects such as reading, mobility and speech. Internship certificates were given to those students over the age of 14 who participated in the year’s work study program.

Along with his graduation certificate, Daquan received a certificate of merit recognizing his community service, presented by the office of New York City Council Member Gale A. Brewer who represents the Guild’s Manhattan neighborhood.

IEP AND ASSISTIVE TECHNOLOGY IN SPANISH

NAPVI Executive Director Susan LaVenture recently hosted a meeting for Spanish-speaking parents of visually impaired and deaf/blind children on the subject of the Individualized Education Plan (IEP) and Assistive Technology.

Dicapta, an Accessible Communications Developer and the Family Center on Technology and Disability presented a video, available at www.dicapta.com, Isabel Necesita Tecnología Asistencia (Isabel Needs Assistive Technology). It illustrates the experience of a Spanish-speaking family who have a child with a disability and the challenges they face.

DELTA GAMMA MEMBERS VISIT GUILD SCHOOL

A group from Columbia University’s chapter of the national sorority Delta Gamma recently paid a visit to the Harriet and Robert Heilbrunn Guild School, where they observed students and teachers at work.

The Delta Gamma Foundation’s philanthropic purpose is to work with individuals who are blind and with the organizations that serve them, through a combination of voluntary service and fundraising.
AT THE GUILD

Guild President and CEO Alan R. Morse, JD, PhD, wrote an editorial “Vision Function, Functional Vision and Depression” JAMA Ophthalmology May 2013, 131(5), 667-668.

GuildNet’s Medical Director Joshua Ardise, MD, MPH, Senior Vice President Quality Assurance/Performance Improvement Laura Brannigan, RN, MA, Medicare Specialist Laura Brosen, RN, MSJ, Diabetes Disease Management Team Program Coordinator Mary-Anne DiNucci, NP, CDE, and Assistant Vice President Quality Assurance/Performance Improvement Michelle Sulfaro, RN, MBA, authored “Integrating Telehealth and Case Management: Lessons Learned from a Diabetes Telehealth Program”, in Case in Point, April 2013, Vol. 11, No. 4.

Elsa Escalera, MD, MPH, joins GuildHealth as Chief Medical Officer. Prior to joining the Guild, she was Deputy Chief Medical Officer, Morris Heights Health Center. She received her MD from the Albert Einstein College of Medicine and her MPH from Columbia University.

George Rowan, MD, joins GuildHealth as a Psychiatrist. Before coming to the Guild he worked at the International Center for the Disabled. He received his MD from the University of Virginia School of Medicine and his BS from the College of William and Mary.

Laura J. Newman, PhD, joins GuildHealth as a Psychologist. Before joining the Guild she worked at the International Center for the Disabled. She received her PhD and her MA from The New School for Social Research and her BPS from the The College of Human Services.

Vision Rehabilitation Projects Manager Yu-Pin Hsu, EdD, OT, SCLV, and Annemarie O’Hearn, MPA, Vice President, Education and Training, presented “Occupational Therapy Strategies for Addressing Low Vision” at the American Occupational Therapy Association’s Annual Conference & Expo in San Diego.

GUILDNET PROMOTIONS

Tamara Romero, MS, has been promoted to Vice President, Business Development for GuildNet. She joined the Guild in 2012, as Assistant Vice President, Business Development.

Jacqueline Anderson, RN, and Andrise Ladouceur, RN, have been promoted to Quality Assurance/Performance Improvement Specialist for GuildNet. Ms. Anderson joined the Guild in 2009, as a Nurse Case Manager and Ms. Ladouceur joined the Guild in 2012, also as a Nurse Case Manager.

Bibiane Sykes, RN, has been promoted to Staff Development Specialist for GuildNet. She joined the Guild in 2012, as a Nurse Case Manager.

Tamara Romero

Elsa Escalera

George Rowan

Laura J. Newman

The Adult Day Health Care Council, at their annual awards luncheon, honored five GuildCare Manhattan staff members with their “15 Years of Service Award”: Miriam Garcia, Madelon Holder, Lyuba Shlepakova, Carol Stokes and Tatyana Ushakova.

Emie Hyman, DPT, joins the Harriet and Robert Heilbrunn Guild School as a Physical Therapist. Before coming to the Guild, she worked for NYL/YAI Lifestart Early Intervention. She received her DPT from the Graduate Center of the City University of New York and her BA from the State University of New York at Binghamton.

Sandria Dougall-Smith, RN; Mandy Edmunds, RN; Shirley Exantus, RN; Gail Giler, RN; Lillian Gleason, RN; Ivy Grace Kirkwood, RN; Zoee Luna, RN; Maureen Stack-Persak, RN, and Patricia Surgeon, RN, join the Guild as Nurse Case Managers for GuildNet.

Jennifer Calcagno, LPN; Phylecia Roberts-Dunbar, LPN, and Barbara Saavedra, LPN, join the Guild as Licensed Practical Nurses for GuildNet.

Marc Goldstein rejoins Guild-Health as a Treatment Coordinator. He previously worked for the Guild from 1994 to 2009, as a Case Worker in the Ryan White Program. He received his BA from Hunter College.

Emie Hyman, DPT

Emie Hyman

Marc Goldstein

Marc Goldstein

PIANO RECITAL A TREAT FOR CLIENTS

Nicholas King, of the organization Art of Giving Back, recently gave a piano recital at our City Center building for Guild School students, GuildCare members and clients from the Mental Health Day Treatment program. His program included two movements from Beethoven’s Moonlight Sonata, a series of Rachmaninoff preludes and Liszt études.

A Los Angeles native, Mr. King is the Founder & President of Art of Giving Back. He received his Performance Diploma from the Glenn Gould School of The Royal Conservatory of Music in Toronto.

Young concert artists who are members of Art of Giving Back perform recitals in the community, mentor young musicians and hold themed concerts that introduce classical music in non-traditional venues. Their website is www.ArtofGivingBack.org.
Guild School students, their families and teachers recently celebrated the wide range of cultures that make up the background of the student body. Students came in costumes that reflected their family heritage. There was dress, for example, that represented family roots in Eastern Europe, Russia, the Caribbean (Jamaica and Trinidad), Latin America, Palestine, Guyana, Greece, Mexico and Italy. Parents brought traditional food for lunch and the event was enjoyed by all.