

POST-POLIO HEALTH

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WWW.POST-POLIO.ORG

A Wonderful Encounter of "Same Here"

Tae Shibata, Kobe Polio Network, Kobe, Japan, translated by Kimiko Negayama, member of the Kitakyushu Polio Network, Kitakyushu, Japan, edited by Joan L. Headley, MS, Post-Polio Health International, Saint Louis, Missouri

"I finally became strong when I accepted who I am. I feel healed every time I experience the feeling of 'same here'."

I was born in 1955. When I was 18 months old, I contracted polio and its after-effects disabled the use of my lower left limb. Since my physical disability was relatively mild, I was able to receive an ordinary education from elementary through senior high school and graduated from university. In the meanwhile, I met no one like me.

I became a teacher because I thought I could work, even with my impaired leg. However, when I was asked to marry, I quit the profession. When I had my first child, I thought, "Finally, I will be accepted by everyone as a woman."

But prejudice and discrimination undeniably exist in our society. When I realized it, I became annoyed and the emptiness and the regrets I had in my adolescence changed into anger. The first "eruption" occurred ten years ago, as a member of the Women's Net Kobe (a group for women's issues). At a meeting focused on the fear of divorce, nondisabled female participants talked about their own experiences and they discussed whether or not they should divorce. I burst into cries. "What are you talking about? You might have various problems, but you can make a decision of your own. I wasn't even regarded as an object of marriage, just because I am lame in my leg." To my surprise, it was something I could not hold in.

Since my childhood, I wished I hadn't been disabled or that I had at least been a boy with a disability. Males with financial ability might be treated as members of society even if they have a physical disability. On the other hand, with women, beauty takes priority over everything. When people talk about "beautiful legs," we are left out. For many years, I was made to believe that females with disabilities should not be treated as independent members of society.

continued on page 2



Kimiko Negayama (▼), Tae Shibata (▼▼) and members of the Japan Network of Polio Survivors (JNPS) at Amity Maishima, Osaka City Maishima Sports Center for Persons with Disabilities.

A Wonderful Encounter of "Same Here"

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Members of the Tokyo Polio Association,
led by Mariko Koyama (▼).



At the age of 39, I realized that this feeling was "silly" and became aware that there must be many women with disabilities who had the same kind of worries as I had. I thought if we could gather together to talk, we might gain the power to liberate ourselves from being dually discriminated against — for being a woman and having a disability.

Nine years ago, I joined a tennis school for the disabled at the Shiawase-No-Mura of Kobe. It was the first time in my life I met a person with aftereffects of polio. Mrs. Azuma and I immediately got along. When I confessed my desire for a mini-skirt and high heels, she expressed her sympathy saying "same here" with a smile on her face.

"Same here." "Same here." Her words were repeated in my mind and gradually grew into delight. This was quite a new feeling. My eyes filled with tears.

In the early stages of our support group, tears were often seen in the regular meetings. Many who attended sobbed out on account of their life as a polio survivor, which brought tears to the other members. Once they spit out what they had in mind for many years, they became happier. They felt reassured by knowing that the rest of the members had the same problems as well.

Our group does aquatic exercise. Swimming is good for us since we do not have to care how much we weigh. When we swim in a swimming pool, we have to expose our legs, so we feel uneasy. But we care less about it when we are together. I'll never forget how comforted I felt when I first saw similar kinds of legs in a row.

While Mrs. Azuma and I engaged in activities to support polio survivors, we learned of the existence of the late effects and post-polio syndrome. Today, we want to help polio survivors, who are over 40 and living in fear of gradually declining physical strength, to accept their new condition and realize that it commonly happens to polio survivors. Moreover, we believe that it is highly possible to avoid having some new symptoms if one is aware of the risks of overdoing in advance.

The Tokyo Polio Association, part of Japan Network for Polio Survivors (JNPS), focuses on medical and scientific information and has distributed their book, *For Understanding Polio and Post-Polio* to major public health centers and hospitals.

JNPS has a representative working with the Japanese with Disabilities National Network, a group dedicated to passing a law to assure people with disabilities have the same rights as other people.

Visit JNPS' website: www.normanet.ne.jp/~polio

I also have changed a lot since I organized this association. I used to lead a difficult life of switching myself from a person with a disability to a nondisabled person since I have mild aftereffects. I finally became strong when I accepted who I am. I feel healed every time I experience the feeling of "same here." ●

My Visit with Japan Network for Polio Survivors (JNPS)

Joan L. Headley, MS, Executive Director, Post-Polio Health International, Saint Louis, Missouri

While in Japan, at the invitation of the Japanese Ventilator Users Network in June, I spent a day with polio survivors in Osaka and another day in Tokyo. I cannot speak Japanese and my gracious hosts supplied translators, but I was immediately struck by the amount of communication that can take place even though there is no common language.



Members of the Tokyo Polio Association with samples of the Walking Bag, luggage that rolls easily in any direction, functions like a walking stick or cane, and is sold by Swany™, a major glove manufacturer. The company's president, polio survivor Etsuo Miyoshi, is the force behind the development of the Walking Bag.

www.swany.co.jp/wb or www.ezswany.com

During our informal week-day meetings of comparing polio and post-polio in Japan and the United States, I learned that the major epidemics in Japan were in 1949-51 and 1958-60, when more than 37,000 children contracted polio. Some children during this time were diagnosed as having "brain infantile

paralysis," which would be diagnosed as cerebral palsy today. The oral polio vaccine was introduced in 1961 and it is now mandatory for all children to be vaccinated.

Interestingly, I heard the polio stories of more than 35 survivors, and nobody was older than age three when they

had polio and most were 18 months or younger. Most of the survivors had attended regular school and had been employed. Many had been diagnosed with post-polio syndrome and were no longer working.

In Japan, people with disabilities can receive a card that identifies them as a person with a disability at a certain level with seven options for classifying their ability. Having the card entitles them to certain services, such as financial support, equipment (e.g., braces, wheelchairs, custom-made shoes), discounts on mass transportation, etc. Some survivors have had a card since they were young and others have recently acquired theirs as a result of having the late effects of polio.

The number of survivors in Japan is not known, but a survey done in Kitakyushu concluded that the number of polio survivors per 100,000 population is 24.1 and the prevalence of post-polio syndrome is 18.0 per 100,000 population. In the survey, 57.2% reported difficulty in climbing stairs and 55.1% reported muscle weakness.

In 2001, the existing eight polio associations (Sapporo, Aomori, Sendai, Tokyo, Nagoya, Osaka, Kobe and Kitakyushu) formed the Japan Network for Polio Survivors (JNPS). Today, 1,200 polio survivors are members of JNPS. ●



My personal translators, polio survivors Yukiko Nakanishi (l) and Haruko Jino (r), at the meeting in Tokyo.



Hiroyuki Naitou, member of the Osaka Polio Network, trying out the iGlide, a computer-controlled wheelchair from Independence Technology, a Johnson & Johnson Company. The iGlide requires minimal effort to control.

www.independence.jp
or www.jnj.com/innovations/new_features/INDEPENDENCE_iGLIDE.htm

Post-Polio, Menopause and Aging: 13 Major Study Points Provide New Knowledge, Clues for Care

Sunny Roller, MA, Program Manager, Physical Medicine & Rehabilitation,
University of Michigan Health System, Ann Arbor, Michigan (elsol@umich.edu)

The nationwide study is finished and the discussion now begins. During the past year, almost 1,000 post-polio women, ages 34 to 99, openly disclosed their menopause secrets with researchers at the University of Michigan. What did we learn and what could this information really mean to women who had polio? When I interviewed chief investigator Claire Kalpakjian, PhD, she clarified the essence of the study's thirteen major findings. We also discussed what each point might tell us about how post-polio women could best care for themselves during their well-earned senior years. Each formal study result warrants a slightly closer look, which is accompanied by this author's perspective: feminine, menopausal, pre-retirement and post-polio.

1. Severity of post-polio sequelae was significantly related to severity of menopause symptoms. One of the study's most important questions asked if worse late effects of polio are connected to worse menopausal symptoms. The answer is "yes." Women with greater post-polio sequelae experienced more menopausal problems in four areas:

- ♦ sensory (numbness, tingling, loss of feeling, constipation, dry eyes);
- ♦ psychological (tense feelings, moodiness, depression, irritability);
- ♦ sleep (sleeplessness, cold hands and feet); and
- ♦ vasomotor (hot flashes, sweating).

There was a link, but one doesn't necessarily cause or predict the other.

What do we do with this information? If a woman knows that her late effects of polio are fairly complicated, she can be on the lookout for the above symptoms and be ready to address them with her physician, as a special prevention effort.

2. Greater menopause symptom severity was significantly related to lower emotional well-being. The worse menopause symptoms are, the more likely one will feel a greater amount of stress, have more negative feelings and feel less satisfied with life.

From this, one might surmise that if we can stay on top of the symptoms with our physicians, then we will end up feeling better about life in general.

3. Menopause status was associated with severity of post-polio symptoms and physical functioning; age-matched men did not significantly differ from women within each menopause status on these outcomes with the exception of late postmenopausal women who reported significantly greater severity of post-polio sequelae than age-matched men. Women who were further along in menopause had more severe post-polio symptoms and more difficulty with activities of daily living than post-polio men their same age. We should seek help for new symptoms. We should take to our physician the brochure, due out soon, that shares the results of this study and discusses the management of polio's late effects.

4. While there were no significant differences by menopause status on emotional well-being outcomes, peri-menopausal women had significantly greater life satisfaction and lower negative affect than age-matched men, and the late postmenopausal women had significantly greater perceived stress than age-matched men.

Women approaching menopause were more satisfied with their lives and less unhappy than post-polio men their age. However, women who were at least five years postmenopause were more stressed out than post-polio men the same age. If we know we might tend to be more stressed after we have been through menopause, then we should take what's known about stress management very seriously and read up on techniques or take a class.

5. Despite unknown elevation of risks of use in the context of physical disability, women in this sample used hormone replacement therapy (HRT) at a significantly higher rate than estimates for their nondisabled peers. Casually stated, more of these post-polio women (39%) were using HRT than their nondisabled sisters across America (23%). We may want to revisit the wisdom of this choice, in light of the new research that has been published in the last year about HRT use.

6. Use of HRT was not associated with better physical functioning or lower post-polio severity nor was it associated with better emotional well-being. The bottom line is that using HRT does not help improve polio symptoms, the ability to do things, or how good a woman feels.

7. HRT use did not mitigate severity of post-polio sequelae or physical functioning by menopause status, but late postmenopausal women using HRT had significantly greater severity of post-polio severity and higher basic ADL functioning than age-matched men. Not only did HRT not alleviate post-polio symptoms, women HRT-users who were more than five years post-menopause actually had worse late effects of polio than post-polio men their same age. This does not necessarily mean that HRT caused the late effects. Also, unexpectedly, despite worse symptoms, the women's ability to do basic self-care tasks was better than the men.

8. Hysterectomy rates among women in this study were significantly higher than the average rate for women in the US. Close to 35% of the post-polio women in this study had had hysterectomies, contrasted to only 21% among American women in general.

9. Age at final menstrual period was average compared to nondisabled women in the US. Both post-polio and nondisabled women across the country had their last period when they were about 50 years old.

10. The experience of menopause among these women was largely positive or neutral. One woman quipped, "Maybe cold polio feet and hot flashes equal out!"

11. Rates of employment of these polio survivors were lower than their similar-aged peers, except for individuals over the age of 65 years who were employed at similar rates as their peers. Polio survivors in the study appeared to have stopped being part of the national workforce earlier than their fellow Americans. This reminds us that knowing the often intricate details of later life planning (finances, housing, health care, transportation, estate planning, etc.) is especially important if we are likely to retire early.

12. Middle-aged (45 to 54 years old) polio survivors reported substantially greater perceived stress than their peers in a national probability sample. Middle-aged polio survivors were more stressed out than nondisabled Americans who were the same age. Once again, managing stress seems to be highly relevant for us.

13. In general, older participants enjoyed greater positive and lower negative mood and perceived stress. Post-polio people who were 65 and older reported less stress and greater happiness than their younger peers. Good news! Indeed, it is true. We get smarter as we grow older!

The final report of Post-Polio, Menopause and Aging project, funded by The Research Fund of Post-Polio Health International, is available at www.post-polio.org/grf-2nd.html.

Interrupted Sleep, Pain and Fatigue ... Not What You Think

Baldwin Keenan, Irvine, California (keenanwhelan@cox.net)

In March 2003, when I told my friends in our post-polio support group that I was only getting one to two hours of solid sleep per night, several of them were convinced that I had sleep apnea. They thought the pain in my left leg and hip was greatly aggravated by the lack of REM sleep.

I contracted polio in 1950 at the age of 2. My left lower leg was affected, but after three surgeries I could walk pretty well and even play some sports. I worked in heavy construction and later spent long hours as a union organizer. In 2000, my left knee snapped while refereeing a soccer game. Susan Perlman, MD, at UCLA, diagnosed post-polio syndrome in 2001. I drastically cut my work hours, but I couldn't seem to significantly bring the pain and fatigue under control. At the urging of Stewart Shanfield, MD (an orthopedist who trained under Jacquelin Perry, MD, and is now at St. Jude Medical Center in Fullerton, California), I retired in August 2002.

Retirement brought great relief from both pain and fatigue for about eight months, and I enjoyed retirement activities such as photography and picture framing. But prolonged walking or standing, even using crutches, started a downward cycle. In April 2003, I explained to Dr. Shanfield that the pain at night was keeping me awake. He advised me to reduce my activities and to bring my conditioning back to the immediate post-retirement level. He sent me to physical therapy twice a week to learn pool exercises for my upper body and "good" leg. He also prescribed a power wheelchair to minimize walking and standing.

None of the above measures improved my sleep, so Dr. Shanfield asked my family practitioner to order a sleep study to rule out sleep apnea. I went to St. Joseph's Hospital where the sleep

lab technicians attached many electrode patches all over my body and fitted me for a nasal mask in case continuous positive airway pressure or CPAP, the standard treatment for sleep apnea, was needed. All the connections were hung in a harness attached to a strap over my neck. Wearing all that gear, I had serious doubts that I would be able to sleep. I managed to sleep for five hours and sleep apnea was not detected.

However, the sleep study detected periodic limb movements: 60 per hour. Peter Fotinakes, MD, of St. Joseph's, evaluated my sleep study and recommended that I consult a neurologist to consider the use of a medication for Parkinson's disease to control the limb movement. The periodic limb movements had prevented relaxation of the muscles in my left leg and hip and, consequently, had exacerbated the pain at night. Stephen Waldman, MD, at St. Jude's, prescribed Mirapex (1 mg) to control the limb movements and Zanaflex (2 mg) to calm the muscle spasms.

The medications brought 4 to 5 hours of solid sleep before pain in my leg and hip would wake me up. I was happy to be making so much progress, but I told Dr. Shanfield that I still didn't feel like I was getting enough sleep. He agreed and ordered a TENS (transcutaneous electrical nerve stimulation) unit. Now when I wake up with pain in the middle of the night, I attach its electrodes to my left hip and knee. I set the stimulus to a comfortable level and usually I am back to sleep in ten



minutes. The stimulus of the TENS unit blocks the "pain message" from getting to the brain.

The result is that I now sleep 7½ to 8 hours a night. My energy level has improved, and I no longer feel fog-headed all day. I've noticed that I'm getting much more benefit from my pool exercises. The night pain hasn't gone away; the TENS unit just lets me sleep through it. To minimize the onset of more pain, I use the power wheelchair often to reduce standing and walking.

The treatment plan I follow works for me, and the periodic limb movements may have nothing to do with the late effects of polio. I caution polio survivors reading this that my condition is particular to me, but we need to share our experiences so others can find different ways to deal with pain and fatigue. What is important in my story is that Dr. Shanfield followed a

Letter to the Editor

"I just received my copy of *Post-Polio Health* and I'd like to add my comments about ventilator users who need a colonoscopy. If they cannot lie down without the ventilator, then the procedure will be difficult, possibly risky and will generate anxiety. My approach is to use the ventilator during and after the procedure so the person is less anxious so less sedating medication is needed, speeding the procedure. Arrangements have to be made in advance with the institution (I agree that the procedure must be in-hospital.), and it is preferable to have the patient's physician make all contacts, set up the ventilator with respiratory therapy and monitor the patient post procedure.

"The bigger problem is when an upper endoscopy is needed and the person uses a nasal or face mask. In that case, I use negative pressure ventilation pre-procedure, so it is not being tried for the first time during the procedure. I also use ventilators for CVT scans and MRIs in the same way, with provisions for longer tubing for those procedures."

Norma M.T. Braun, MD, St. Luke's-Roosevelt Hospitals
New York, New York

scientific method to treat my pain. He thought my problem might be breathing-related sleep apnea, but the data of the sleep study did not support his original conjecture and the results guided him in successfully resolving my pain and fatigue. ●

New Books

Paralysis Resource Guide (2003) is a colorful, comprehensive, 310-page, spiral-bound resource by Sam Maddox. Contact the Christopher and Dana Reeve Paralysis Resource Center (www.paralysis.org, 800-539-7309 toll-free).

I'd offer you my seat ... but it's taken, is a soft-cover 72-page book by Ralph M. Scott of Alabama, that candidly shares his life story with numerous anecdotes that exhibit his observational abilities, his sense of humor and his faith. Send \$4.00 to John N. Clayton, Does God Exist?, 1555 Echo Valley Drive, Niles, Michigan 49120.

The following books are available from Barnes and Noble and Borders, or on www.Amazon.com.

Broken Yesterdays, is a memoir by the late Joseph William Meagher, focusing mainly on the years he spent in the late 1920s and early 1930s at the St. Charles Hospital School in Port Jefferson, Long Island, New York.

Voices from the Edge: Narratives about the Americans with Disabilities Act, is compelling fiction and nonfiction by the disabled. Edited by Ruth O'Brien, Professor, John Jay College of Criminal Justice, and Chair of Political Science MA/PhD Program, Graduate Center, City University of New York.

The Glycemic Index: Good Carbs, Bad Carbs

Jann Hartman, Baltimore, Maryland

One of the most frequent dietary suggestions I have received is to eat “low glycemic foods.” The Glycemic Index (GI) is a numerical ranking of foods showing how quickly they are broken down into sugars after a meal as compared to a standard (usually glucose). While the index can be a useful tool (similar to calorie counting), the GI rating of any one food also depends on a variety of other factors. “People think that a food has a definitive glycemic index, but it depends on how the food is processed [or not], stored, ripened, cut and cooked,” states Xavier Pi-Sunyer, an obesity expert at Columbia University, College of Physicians and Surgeons in New York.

First, all foods are made up of proteins, fats and carbohydrates. These three nutrients are essential to our bodies and so is the proper daily intake. It is important for us to make better choices about food, especially carbohydrates — a fuel for our bodies. Our goal should not be to restrict any essential part of a healthy dietary plan, such as carbohydrates, but to choose them well.

DEFINITION OF GLYCEMIC INDEX

The glycemic index (GI) expresses the rise in blood glucose elicited by a carbohydrate food as a percentage of the rise in blood glucose that would occur if the same individual ingested an equal amount of carbohydrate from white bread or glucose. Increased use of low GI foods such as legumes, barley, pasta and whole intact grains (e.g., cracked wheat) may help improve blood glucose control and allow carbohydrate intake to be increased without raising serum triglycerides.

What is a “good carb”? We should be eating a variety of carbohydrates consisting of fresh vegetables, fruits and whole grains instead of those that have been highly processed, e.g., sweetened cereals, cakes, cookies or candy. You may have heard that it is best to eat *complex* carbohydrates and not *simple* sugars. While this is not a bad place to begin, it is not the whole story. Some simple sugars are actually good for you (e.g., flavored yogurt, fruit), while some complex carbs or starches (e.g., white bread, potatoes and pastas) are not as good for you because they raise your blood sugar levels.

Since not all carbs are equal, we need to fuel our bodies with healthier choices. I have learned that it is best to eat a variety of foods in as close to their natural state as possible. This simple advice is still as true today as it was when I first heard it. When I stray too far from this advice for too long, my body and blood sugar pay the price.

Carbohydrates provide that important part of our food — fiber. It helps lower the impact of the simple sugars we eat (e.g., fructose in fruits). Remember, whole grain flours, which are rich in fiber, are much more nutritious than white flours that have been processed removing essential nutrients. Even “enriched” white flour does not restore all the nutrients removed during processing.

Jennie Brand-Miller, author of the book *New Glucose Revolution*, reminds us, “The foods that provide the most carbohydrate in the diet are the ones that need close attention (potatoes,

While the index can be a useful tool (similar to calorie counting), the GI rating of any one food depends on a variety of other factors.

breakfast cereals, breads, soft drinks) not carrots, honey or over-ripe bananas.”

Do you have to give up all the foods you love? Of course not! I enjoy an occasional cookie. But, when I do, I choose a healthier alternative such as oatmeal nut cookie instead of a store-bought sugar cookie. And, occasionally, I splurge on a small amount of ice cream or chocolate, savoring every bite. But, when planning my daily diet, I choose the most nutrition I can get for my money and my health by including fresh fruits, a variety of vegetables, and wholesome whole grains. ●

Other interesting note: The role of the GI in diabetes therapy is controversial. The GI is not endorsed by the American Diabetes Association, but is recommended by the Diabetes Nutrition Study Group of the European Association for the Study of Diabetes and by the World Health Organization. There is concern that including GI information in nutrition teaching is too complicated and limits food choices.

Source: Guidelines for the Nutritional Management of Diabetes Mellitus in the New Millennium: A position statement of the Canadian Diabetes Association.

Low Glycemic Index Foods

(Choose these foods more often)

Food	Glycemic Index
Popcorn	79
Oatmeal (slow-cook oats)	70
Parboiled rice	68
Pumpernickel	66
All-Bran™	60
Sweet potato	54
Skim milk	46
Pasta	40-70
Lentils/kidney/ baked beans	40-69
Apple, banana, plum	34-76

High Glycemic Index Foods

(Choose these foods less often)

Food	Glycemic Index
Instant rice	124
Corn Flakes™	119
French fries	107
Soda crackers	106
Potato (boiled/mashed)	104
White bread	100
Couscous	93
Ice cream	87
Oatmeal (1-minute oats)	87
Table sugar (sucrose)	83

Source: www.diabetes.ca/Section_About/glycemic.asp

The Research Fund of PHI

Thanks to an additional donation of \$21,000 from the estate of Thomas Wallace Rogers and donations from you, our members, The Research Fund of Post-Polio Health International now exceeds \$355,000.

THE 2005 AWARD

The five members of the Review Panel are now evaluating applications for the third award of \$25,000 to be announced this fall. Seven researchers of the thirteen original applicants were asked to submit the requirements for Phase II of the selection process. The next Call for Applications will be issued in 2006.

See pages 4-5 of this issue of *Post-Polio Health* for a summary of the 2003 award given to a team of researchers at the University of Michigan, Ann Arbor.

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IN MEMORIAM

Hugh Gallagher, 1932-2004

Hugh Gallagher, a member of PHI's Honorary Board, died July 13 at the age of 71. Gallagher contracted polio in 1952 while attending college. He received rehabilitation services at the Georgia Warm Springs Foundation where he met former first lady Eleanor Roosevelt.

A disability rights activist and historian, Gallagher was acclaimed for his 1985 biography, *FDR: The Splendid Deception*, about the effects of polio on Franklin Delano Roosevelt's life and presidencies. Gallagher was instrumental in the addition of the statue of Roosevelt in a wheelchair to the Franklin Delano Roosevelt Memorial in Washington DC.

Gallagher wrote the first disability civil rights law — the Architectural Barriers Act of 1968 and was often considered the "grandfather" of the Americans with Disabilities Act.

New Jersey Polio Network Honors PHI



Joan L. Headley, Executive Director, PHI, and Frederick M. Maynard, MD, President of the Board of Directors, accepting an award "for dedicated service since 1958 to polio survivors and ventilator users" from Jean Csaposs, President of the New Jersey Polio Network, at their 14th Annual Conference on Post-Polio Syndrome, April 25, 2004.

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THE MISSION OF POST-POLIO HEALTH INTERNATIONAL, including *International Ventilator Users Network* ... is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

REMINDERS ...

Ninth International Conference on Post-Polio Health & Ventilator-Assisted Living: STRATEGIES FOR LIVING WELL

June 2-4, 2005

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MOVING???

Contact Justine Craig-Meyer at 314-534-0475 or
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People with disabilities in the US register to vote at a
rate that is 16 percentage points less than the rest of the
population. Of the 54 million people with disabilities,
only 35-45% vote. **Are you registered to vote?**

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