**February Newsletter**

**Glaucoma Awareness Month (January) and Rheumatoid Arthritis Awareness Day (Feb. 2nd)**

Written by Judy Wieber

January is Glaucoma Awareness month and February 2nd is Rheumatoid Arthritis Awareness Day. I feel compelled to write about both diseases, since I know what it is like to live with both.

When you hear of someone having arthritis or glaucoma, you usually tend to think of an older person, but not in my case. I was under the age of one when they discovered I had Juvenile Rheumatoid Arthritis (JRA), and I was about four years old when the eye doctors diagnosed the glaucoma. In fact, the glaucoma is secondary to the JRA. Researchers have now found that it may have been the medicines used to treat the inflammation in my body, which caused glaucoma and cataracts. Today, when a child is found to have JRA, or now called Juvenile Arthritis (JA), they no longer treat it with the same medications.

The form of JRA I had is exceedingly rare. It is found mostly in girls. This specific type of arthritis causes inflammation in the eyes and usually one or two weight bearing joints. In my case, it caused inflammation in my right knee joint and both of my eyes. The inflammation caused by JRA is severe and is like that found in the adult Rheumatoid form. Thankfully, most who have this type of juvenile arthritis no longer have symptoms once you reach your teen years, and inflammation is minimal. It is not caused by the wearing away of cartilage, as seen in Osteoarthritis (OA). OA is commonly found in most people as we age and spend a lifetime using our healthy joints.

JRA is an auto immune disease, meaning that the body sends an immune response unnecessarily to attack healthy tissue. Our bodies send immune responses, inflammation, to attack infection, and to aid injured tissues. But in the case of autoimmune diseases, the body is found attacking perfectly healthy tissue, causing damage.

In my case, I started to crawl, and then stopped. My parents noticed that my right knee was very swollen. They were overly concerned and troubled, because I had not had any trauma to my leg or knee to have caused the swelling. They then took me to my pediatrician who ran some tests which included a blood test. The blood work showed an elevated Sed rate and a positive ANA. Which was indicative of the JRA, along with the swelling. My parents then were told to take me to a Rheumatologist who put me on a regiment of aspirin and prednisone. The Rheumatologist then sent us to an Ophthalmologist who examined my eyes with a slit lamp, finding uveitis, inflammation of the eye. Uveitis alone can cause blindness, so they had to work quickly, using cortisone shots into the eye to reduce the inflammation. The shots along with a regimen of anti-inflammatory eyedrops knocked out the uveitis, but the result caused cataracts and glaucoma. The cataracts were surgically removed, and bi-focal glasses were prescribed, so I could see. This was prior to the surgeries they now have today where they can insert a lens right into the eye after removing the clouded lens.

The glaucoma was treated. Unfortunately, glaucoma is not a curable disease, but rather it is something, in most cases, treatable. Surgery and eyedrops are commonly used to slow the progression.

Glaucoma is an eye disease that is like a thief in the night, gradually robbing people of their vision without much warning. It is so important for anyone over the age of 40, to have an annual eye exam which includes a glaucoma test.

There are many causes of glaucoma; some are genetics, some are the result of injury to the eye.

Some signs of glaucoma are:

A headache over the eye across the eyebrow.

Halos or rainbows around streetlights at night

Bumping into things consistently on one side of the body, that you are not picking up in your peripheral vision.

Nausea and vomiting.

Glaucoma is an eye disease that can cause permanent and irreversible damage, if not treated, or caught in time it can cause blindness. It causes elevated inter ocular pressure, resulting in optic nerve damage.

To learn more about Juvenile Rheumatoid Arthritis, or Glaucoma you can visit the Arthritis Foundation at website: https://www.arthritis.org/ or The Glaucoma Foundation website at: <https://glaucomafoundation.org/>

**Advocacy and Empowerment**

Written by Judy Wieber

Despite the trials and tribulations of Covid, RSV and the Flu, the Advocacy and Empowerment team under the direction of Marilyn Tucci has been working earnestly on New York Senate bill S4242, sponsored by Senator Alexis Weik of New York Senate district 8. They have now gotten a complimentary bill in the Assembly: A 8277. Sponsored by Assemblyman Scott Bendett of Assembly District 107, along with eight co – sponsors: Assemblyman John Mikulin, Assembly District 17; Assemblyman Michael Durso, Assembly District 9; Assemblyman John Lemondes, Assembly District 126; Assemblyman Brian Manktelow, Assembly District 130, Assemblyman Joe DeStefano, Assembly District 3; Assemblyman Chris Tague, Assembly District 102; Assemblyman Anil Beephan, Assembly District 105; Assemblyman Ari Brown, Assembly District 20.

Bills S4242 and A8277: “An Act to amend the public health law, in relation to requiring telephones capable of making local and long-distance phone calls in every nursing home patients’ room, or bedside, dependent on the patients’ ability..."

It presently sits in the Health Committee in both Senate and Assembly.

Imagine if you lived in a nursing facility and was only granted access to local phone calls. You could not call friends or family out of state, you cannot access telehealth services out of the local area. You cannot access public meetings and voice your opinion about critical issues that may affect your living. Presently, not all patients are permitted to make out-of-the-area phone calls from the privacy of their room. Those who are permitted, have to be brought to the nurse’s station. Calls from the nurse’s station are limited in the amount of time they can spend on the call. How would you feel? What would this mean for you?

If this is a law that you would like to see come to fruition, then call Marilyn Tucci, director of SILO’s Advocacy team: (631) 880-7929 Ext. 125. They will be happy to explain how to find out who your legislators are, how to write a letter, and how to track bills.

**French Toast Casserole**

The following recipe was submitted by Morgan Suchy, SILO intern.

With February being a month for love, why not make a nice breakfast for the ones you love?

French Toast Casserole

 1 loaf of white bread, cut off the crusts.

 2 cups milk

 1 stick butter, melted.

 1 cup light brown sugar

 1 tsp cinnamon

 5 eggs

Preparation

 Make sure the crusts are cut off all bread slices.

 Mix butter, brown sugar, and cinnamon.

 Spread butter mix on the bottom of a 9x13 pan.

 Double layer bread, make sure ends touch.

 Beat eggs and milk; pour over bread.

 Sprinkle with cinnamon and cover with plastic wrap overnight in the refrigerator.

Bake at 325℉ for at least 30-45 minutes. Casserole should be soft (but still fully cooked) in the middle, and firmer on the edges.



**A Journal for Jordan**

Written by Judy Wieber

Since Valentine’s Day is in February along with February being Black History Month, I have chosen “A Journal for Jordan” as my movie pick for this issue. It is based on Pulitzer Prize winner, and New York Times Journalist, as well as the first woman of color to hold the position of Administrator of Pulitzer Prizes at Columbia, Dana Canedy’s true account of her love story with 1st Army Sergeant Charles Monroe King.

The film is co-produced and directed by Denzel Washington.

Described as a story of love, commitment, and valor, Journal for Jordan is a film not to be missed.

Chante Addams plays Dana in the film and Michael B. Jordan plays Sergeant Charles Monroe King. The two fall in love and enter an intimate and committed relationship. The couple give birth to a beautiful baby boy, Jordan. Sergeant King Shortly after Jordan’s birth is called back to serve in Iraqi Freedom. Before he goes, realizing the dangers of the tour, Dana gives him a journal to keep while away. Unfortunately, he gets killed and the journal is brought back to Dana. Dana keeps the journal for their son to read when he is older and needs the guidance of his father whom he never got to know.

The ending has a powerful impact as their son can bring honor and closure, about the passing of his father, presenting an American flag to his mother in a military family ceremony.

**February 29th 2024 marks the 14th Anniversary of SILO's Peer Support Group run by Advocacy Director, Marilyn Tucci!**

Interested in joining this group?
Call: (631) 880-7929 Ext. 125
or email: mtucci@siloinc.org



**World Braille Day**

Written by Judy Wieber

January 4, 2024, was the 5th annual celebration of World Braille Day.

It has been reported that less than half of people who are blind or visually impaired are employed. About 85% of these working people read braille. Looking at these statistics, it makes sense to teach braille as a valuable tool in overcoming barriers of independence and employment.

To encourage braille usage, The National Library Service for the Blind and Physically Handicapped has electronic Braille Readers on loan to eligible patrons. The device is equipped with a 20-braille display, a chargeable battery, and a lanyard, making it ready and portable. Contact the Andrew Heiskell Braille and Talking Book Library to learn more at: (212) 206-5400.

**NYS Executive Budget 2024-2025**

Written by Judy Wieber

I recently was given the opportunity to review NYAIL’S analysis of the proposed New York State Executive budget for 2024/2025.

On July 1, 2024, the participation of public meetings by video conferencing will be sunsetting. We are being asked to talk, call, or write our state legislators on extending this bill not only for two years, but permanently. Being given access to public meetings by video conferencing allows for more people to attend, voicing their opinions and needs. A broader section of the public can be heard from, about what matters. Transportation and building accessibility are no longer an issue. We have the technology, and we know it works. In my opinion, this is the most important thing to the community of disabled people, as a result, of Covid-19. Let us keep the right to take part without the worry of travel. Let us make it a permanent Open Meeting Law now. This can only happen if we let our voices be heard.