ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside MM Support Group

Business and News:

Thank you, Nancy B, for hosting the September meeting at Emory St. Joseph's Conference Center. There were 17 in person and 15 online in attendance. Our guest speaker was Kim Burney, oncology educator at Johnson & Johnson. She has been a career oncology nurse for 37 years. Her presentation focused on bispecifics in relation to J&J products for myeloma.

Guest Presentation

Kim began her talk with the development of Darzalex. She started her career in oncology when there were very few options for myeloma patients, and the life expectancy was one to three years. She is excited about all the new therapies now available to patients. J&J has developed five lines of treatment for myeloma that provide longevity of survival with improved quality of life.

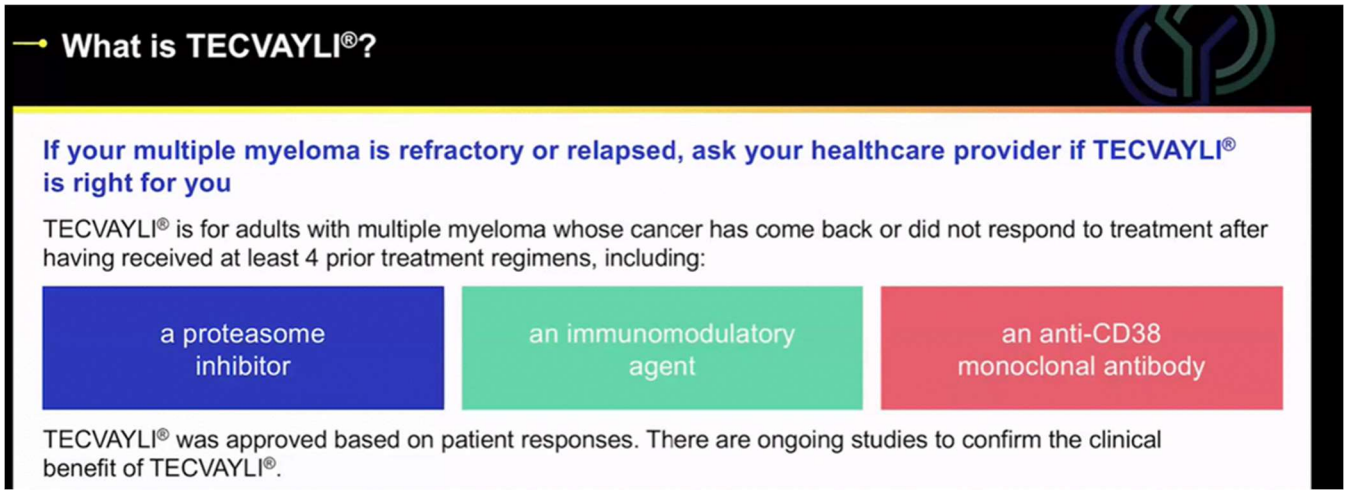
Darzalex (daratumumab) was the first MM drug that treats patients with a monoclonal antibody targeting CD38 on the surface of the myeloma cell. It has been on the market for over 10 years, first as an IV infusion, now as a sub-Q injection as well. Carolyn H. was on the clinical trial at Emory and attained PFS for almost 13 years. J&J enhanced the drug in 2020 with a sub-Q injection making Darzalex Fast-Pro the preferred method of delivery.

Darzalex has been in the forefront of myeloma treatment for over ten years. It is used in most treatments for NDMM using a four-drug combination as initial therapy. The long-term response generally lasts longer than the previous standard of care. It is a monoclonal antibody which means it attracts and binds to the CD38 protein target that is on the surface of the myeloma cell to help the immune system kill the myeloma.

Bispecifics Tecvayli and Talvey

Tecvayli is the first bispecific developed by J&J and has been on the market about 3 years also known as *Teclistamab*. A bispecific has two arms, one attaches to the myeloma cell and the other to the T-cell.

What is Tecvayli? How does it destroy myeloma? **Tecvayli binds to the target on the surface of the myeloma cell called the B-cell maturation antigen (BCMA). BCMA receptors express on the surface of the myeloma cell to keep myeloma mutating and growing. When one path is blocked, the receptors move elsewhere so the drugs need to block as many pathways as possible to stop myeloma progression. This bispecific binds on the myeloma cell and then attaches to the CD3 target on the patient's T-cell. When the T-cell and myeloma cells come close together, the bispecific helps the T-cell kill the myeloma cells.**

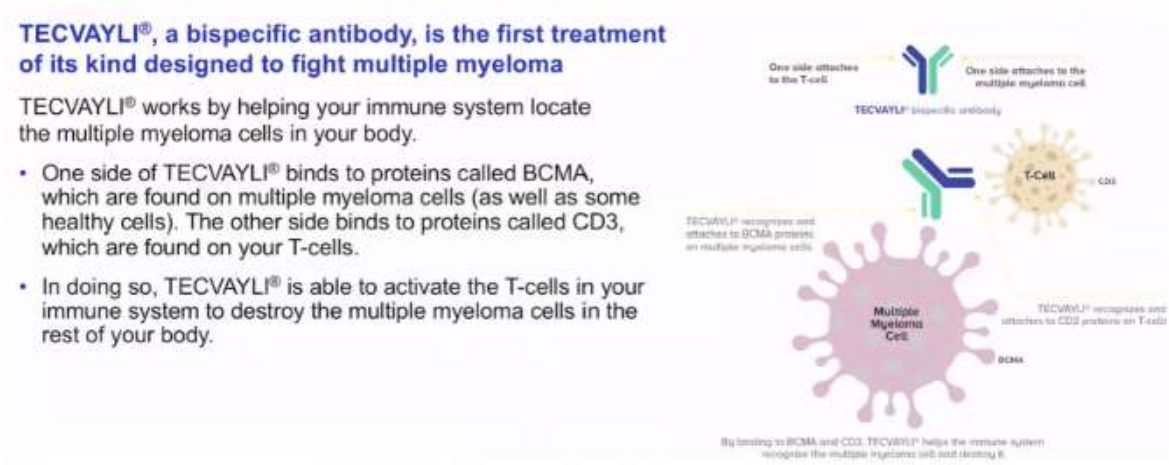


There are two major side effects that occur when patients are treated with bispecific therapy. It causes the release of pro-inflammatory cytokines known as Cytokine Release Syndrome (CRS) as well as neurological issues (ICANS). Patients receive step-up doses starting with small doses to reduce the severity of CRS. This dose escalation is done in a bone marrow transplant facility or cell therapy units that are accustomed to monitoring for major side effects such as cytokine release and neurological issues. Now that the drug is three years old and the major side effects have been controlled, we no longer have to hover over the patient like a newborn. Incidents of Stage 3 or 4 CRS and ICANS have been reduced to manageable side effects. Cytokine release and the neurologic issues are not as adverse as in the past, so bispecifics can now be given outpatient in many facilities as step up dosing. To qualify for this treatment, patients must have received four prior lines of therapy from three drug classes: PI, IMiD and anti-CD-38 monoclonal antibody.

Newly diagnosed patients must wait before being eligible for Bispecifics or CAR-T therapy. After the fourth line of therapy, you may qualify to receive bispecifics.

Note that changes in your treatment plan may include disease progression, drugs becoming refractory or no longer effective, patient intolerance and adverse side effects. Once this occurs during four lines of treatment, you become eligible for bispecific therapy. For example, when newly diagnosed patients are treated with Darzalex, Revlimid, Velcade and dexamethasone followed by ACST, that is considered the first line of treatment. Three additional lines of therapy need to be used before the patient qualifies for a bispecific.

This is a good illustration that shows how it binds.



Here are the results for Tecvayli as a monotherapy. Some patients may still be on trial.

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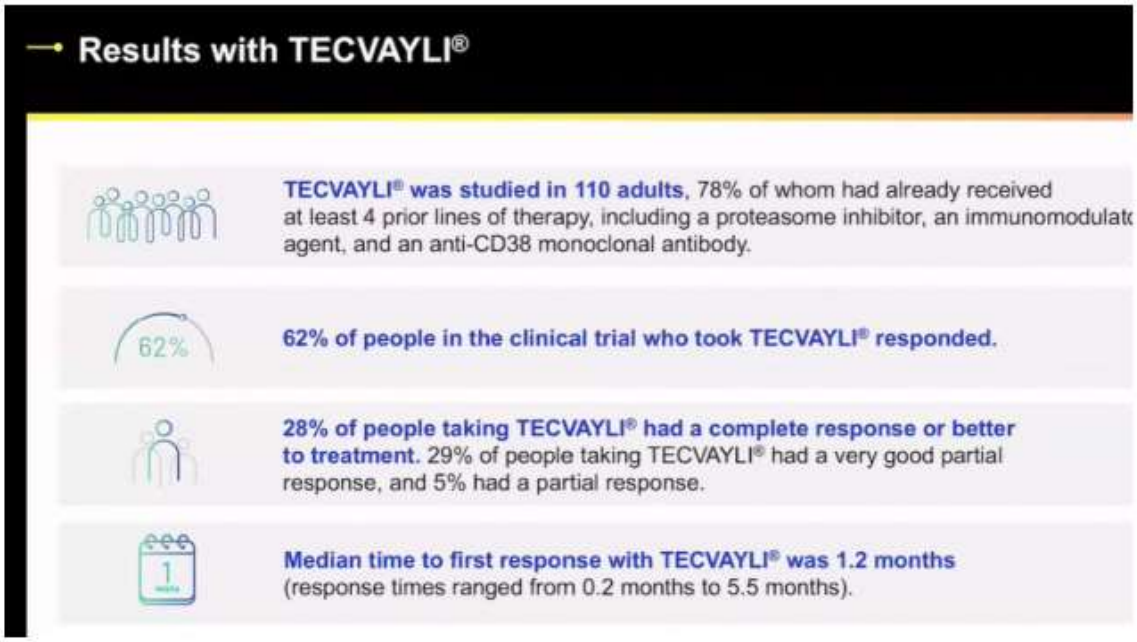

· **The same results occurred with Darzalex monotherapy 10 years ago with an overall response rate of 28%. Since both drugs started as single agent therapies combining them with other effective drugs can make the treatment more durable with promise of deeper, longer response rates.**

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What is the most important information I should know about TECVAYLI®?

TECVAYLI® may cause side effects that are serious, life-threatening, or lead to death, including Cytokine Release Syndrome (CRS) and neurologic problems.

Call your healthcare provider right away if you develop any of the signs or symptoms of CRS or neurologic problems listed below at any time during your treatment with TECVAYLI®:

Cytokine Release Syndrome (CRS). Signs and symptoms of CRS may include:		
• fever (100.4°F or higher)	• dizziness or lightheadedness	• confusion or restlessness
• difficulty breathing	• fast heartbeat	• headache
• chills	• feeling anxious	• increased liver enzymes in your blood

Neurologic problems. Symptoms of neurologic problems with TECVAYLI® include:		
• headache	• confusion	• changes in your handwriting
• jerking movements	• trouble speaking	• problems walking
• rigid muscles	• muscle spasms	• muscle weakness in your body or face
• feeling restless	• tremor	• hearing loss
• numbness and tingling (feeling like "pins and needles")	• double vision	• burning, throbbing, or stabbing pain

· **CRS symptoms generally occur in the first ten days during the step-up dosing period. Doctors are watching your labs closely. You need to *speak up* if there is anything wrong or unusual, particularly if you develop flu-like symptoms or sepsis causing infection to take over your immune system. Doctors may hold the dosing or modify treatment protocol to normalize your blood system. Remember your immune system is compromised and not functioning properly.**

· **The next concern can be neurological issues. Initially you start getting cognitive issues, being confused or disoriented, or your speech is slurred. That is caused by Immune Effector Cell Associated Neurotoxicity Syndrome (ICANS). Dexamethasone is given,10 milligrams IV every 6 hours to combat the effects. The side effects listed in the chart above are monitored and the caregiver plays a critical role in keeping the medical team informed.**

The group talked about the Emory Immediate Cancer Care (ICC) which is available 24/7, Monday through Saturday, in the Tower building, fourth floor, at the Clifton clinic or at the Winship -Emory Midtown location Sunday through Friday. You need an appointment to get into ICC as a cancer patient with an emergency. Call the main Emory triage line (404-778-1900), day, or night, and tell them you are having symptoms from cancer treatment. The Emory triage call line will transfer you to ICC.

One caveat, CAR-T patients have to go over to the main campus on Clifton Road. Midtown is not set up for CAR-T patients yet. By the end of this year, both locations will be open 24-7. There is a wallet card that comes with bispecific instructions, please carry it. Here is why. You are doing great, feeling good. Then you go out of town and end up in the hospital with a fever. The healthcare team needs to know that you are on bispecifics to interpret blood work and treat you appropriately.

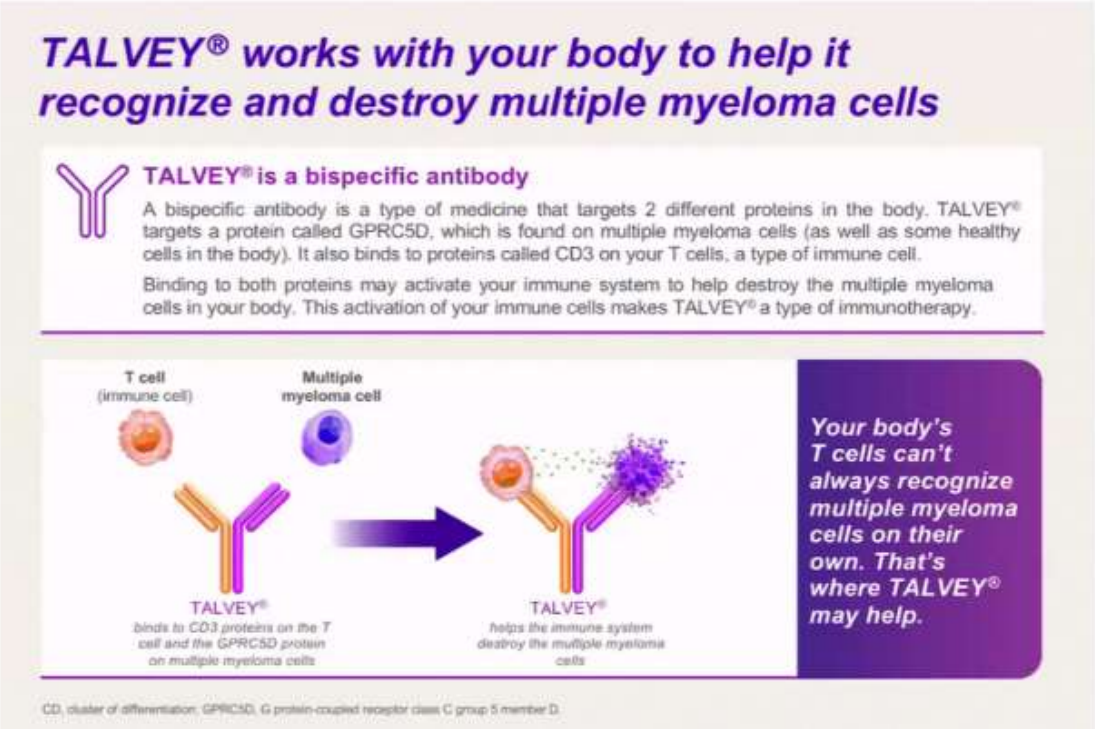
In summary, bispecifics have two main treatment side effects, cytokine release syndrome (CRS), and neurologic issues (ICANS). Do not forget the third side effect*; infection*.

Bispecific as well as CAR-T drops the white blood cell count drastically, and when your immunity plummets, you are susceptible to many issues, particularly infection. Any kind of fever is a red flag to call your provider right away. Start calling when your temperature rises above 99. Do not wait until it goes over 100 degrees, especially if your baseline is under 98 degrees. You need to catch the symptoms of CRS and ICANS before they cause major problems in your recovery. Myeloma is a B-cell malignancy. B cells are part of the

immune system, so even at diagnosis the plasma cells have been affected and maybe immunocompromised. A patient's white cells also become compromised from the treatment drugs received during all lines of therapy.

Remember, myeloma is a cancer of the immune system.

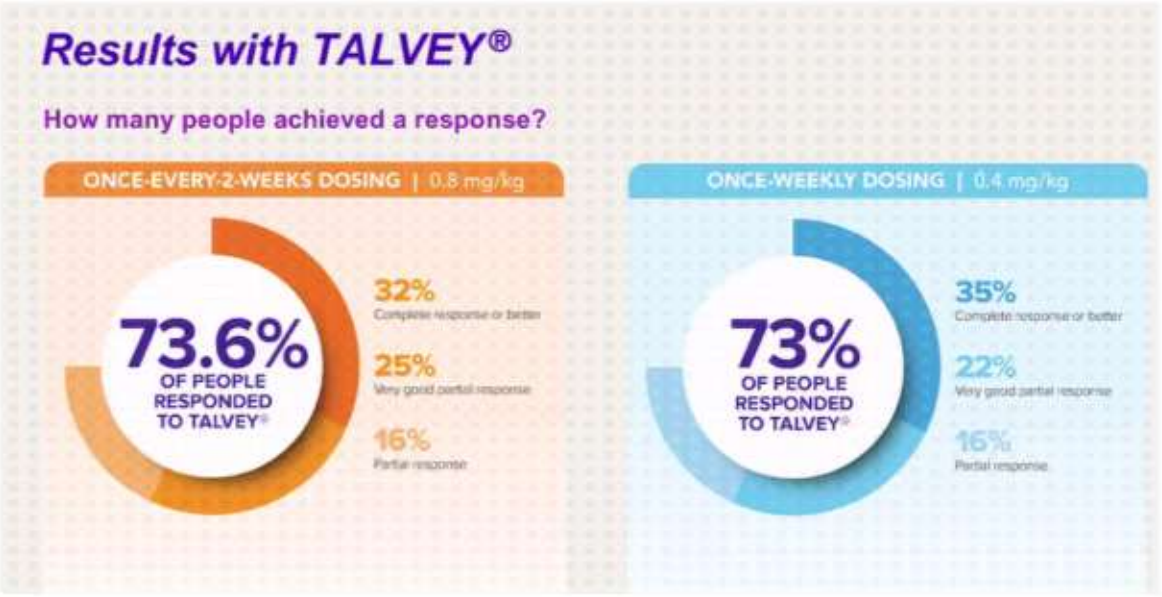
Talvey **is a bispecific with a different target. Talvey has a similar mechanism of action, but different targets on the myeloma cell. Patients must have received at least four prior lines of therapy to qualify, and the prior treatments must include three drug classes: a proteasome inhibitor, an immunomodulatory agent, and an anti-CD38 monoclonal antibody.**



Talvey is the orange and purple arms in the middle, binding to the myeloma cell and the T cell and helping to destroy the myeloma cell.

Talvey has a bi-weekly dosing option off the bat. You still have to go through step-up schedule, but you can either get 0.4 milligrams per kilogram weekly or 0.8 biweekly. With both drugs, you take it until you progress or develop some toxicity that cannot be overcome. Clinical trials are studying the possibility of increasing the length of time between doses.

· **The current treatment protocol for bispecifics is to continue treatment indefinitely until the myeloma relapses or disease progression. There are no plans for in-home injections currently.**



· **Talvey has the same mechanism of action as Tecvayli, but it just targets a different antibody on the myeloma cell. The target on Talvey is GPRC5D. It is also expressed on your epithelial cells, so you can have mouth, nail, and skin issues with Talvey that you do not have with Tecvayli. Taste is one of the side effects that is slow to recover and may never come back completely. Your labs are monitored closely, and treatment is put on hold if your bloodwork is out of range until it comes back to normal perimeters. There may be continual adjustments during the initial course of treatment.**

· **Even though your cells are not 100% healthy after four lines of therapy, bispecifics are still targeted therapy that is killing myeloma. Talvey and**

Tecvayli are not given together because it is not FDA approved therapy. It is not combined with Darzalex, Revlimid, or anything yet. However, clinical trials are exploring combinations and looking at how to move bispecifics up to earlier lines just like CAR-T therapy is now a second line treatment option.

· ***Can patients be tested to identify which is their primary target on the myeloma cells?*** **All myeloma cells have these targets, CD38, BCMA.GPRC5B, and SLAM-F7. There are drugs available targeting all of these, which makes a good argument for combining therapies to kill these smart myeloma cells with multiple targets simultaneously. There is a tri-specific in clinical trials which binds to two different targets on the myeloma cell and attracts the T-cell to kill the myeloma. There are trials with two bispecifics or a tri-specific to go after more than one target at a time. We will be watching the news on these trials reported from the ASH conference in December.**

Submitted by Sandy W

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Meeting Minutes

Southside MM Support Group

September 27, 2025

Next Meetings:

Southside Meeting is Saturday, October 25, 2025 @ 10:30 AM. Hybrid – In-person and online virtually. Patient and Care Partner Voices

For Men (with Myeloma) Only. Tuesday, October 28, 2025 @ 6 PM. Virtual.

News and Business

Southside members participated at the Atlanta/East Point community Health Fair on September 20. Thanks to Joyce J., Nancy B., and Doris who shared myeloma info and uplifting messages. Only one week before the annual Light the Night with Blood Cancer United aka Leukemia and Lymphoma Society on October 4. We were able to exceed our goal of $3000. Thank you to all who contributed this year.

The Southside meeting was canceled for October so members could attend the Atlanta Myeloma Roundtable featuring Drs. Nooka, Hofmeister, Nishi Shah, Richa Parikh, and Nisha Joseph from Emory Winship. Healthtree sponsored the event at the Marriott Marquis in Atlanta. There were several important messages communicated during the Myeloma Roundtable from both Dr. Hofmeister and Dr. Nooka:

1. Every Myeloma patient needs to see a specialist who treats myeloma every day. This can be in the form of a second opinion or consultation, not necessarily changing doctors. Myeloma is still a rare disease with new treatments being introduced frequently. It takes someone who is current on all the new findings in myeloma to provide the best treatment for their patients.

2. Knowing what type of myeloma you have, IgG, IgA, etc. is important. Also know whether you have high risk or standard risk myeloma and what makes your myeloma high risk is most important. You can follow treatment options when you know this information.

3. Take measures against shingles by taking Acyclovir and Valacyclovir. It is cheap and effective with very few side effects.

4. Note that if you are taking Revlimid or Pomalyst there is triple the risk of blood clots and double the risk of heart attack and stroke. **Pay attention to any symptoms.** Ask about preventive medications.

Additional topics from the round table sessions included:

Dr. Hofmeister: **Revolutionary Early Myeloma Care.** The latest breakthroughs in myeloma treatment and new frontiers – quadruplet therapies and immunotherapy in newly diagnosed myeloma (NDMM) patients.

Dr, Nooka: **Game-changers in Relapsed and Refractory Myeloma (RRMM) -** *Navigating choices***.** An overview of emerging RRMM treatment options and clinical trials. Also. the role of clinical data in advancing myeloma research.

Dr. N. Shah: **Bispecific Antibodies –** *Myeloma's New Frontier*.

Dr. N. Joseph: **Today's Advancements, Tomorrow's Breakthroughs –** *CAR-T, CELMoD, and Beyond.*

Breakout sessions on Nutrition and Ensuring Equity and Black Myeloma Patient Care.

To replay the conference, click Healthtree ATL Round Table Event .

The event was supported by several pharmaceutical companies who were present with information to share with patients, care partners, and supporters. They included GSK, Sanofi, Johnson & Johnson, Pfizer, Bristol Myers Squibb, Karyopharm, and Legend.

Reference:

CelMoD is a protein and the scientific shorthand for 'Cereblon E3 ligase modulator. Nearly all multiple myeloma patients have been heavily involved with Cereblon E3-, the target of the immunomodulatory drugs. Revlimid, Pomalyst or Thalidomide.

Respectfully submitted,

Gail