

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Meeting Minutes

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March 1, 2025

#### Business News and Upcoming Events

Thank you, Nancy B, for hosting this month's meeting and presentation on Estate Planning. Over forty participants were in attendance virtually. Our guest speaker was Joanna Doran, CEO of Triage Cancer. Northside AAMMSG will not be meeting next month to make way for the IMF **Regional Community Workshop (RCW) in Atlanta on April 5, 2025, from 8 a.m. to 4 p.m.** at the Sheraton Suites Galleria, 2844 Cobb Pkwy. SE, Atlanta. GA. The workshop is free and includes lunch. Registration begins at 8am and speaker presentations start at 9 o'clock. *Seating is limited so be sure to **register** right away.* Visit [myeloma.org](http://myeloma.org) for more information on speakers and the scheduled myeloma topics.

#### Guest Presentation

Joanna started her presentation with an overview of [TriageCancer.org](http://TriageCancer.org). She is the co-founder and CEO of the nonprofit organization and is trained as a cancer rights attorney. Triage Cancer provides free education on legal and practical issues that evolve with cancer diagnosis including insurance, unemployment, estate planning and finance concerns. The website offers free resources on these topics. Estate planning is a topic that seems far more complicated than it really is. It conveys your desires regarding personal property disposition, health care directives and end of life instructions to be carried out if you are incapacitated or at the time of death. If these details are not written down in advance there is no guarantee that your wishes will be carried out.

The reality *is* that every single one of us will pass away. **Estate planning** is not a popular topic that anyone wants to talk about or even think about. Much like having to file your taxes or pay your bills. It involves collecting and organizing key documents to be kept together in one place for easy access. This is particularly important for you and for those that will need access in the future. There is an array of documents to consider including *power of attorney* for financial affairs, *healthcare directive* for medical decisions, a *will and/or trust* for estate disposition to name a few. These documents address decisions on finance, healthcare needs, and practical matters if you become incapacitated and at death. To start the process, ask these **big picture questions**:

- What happens to my personal property when I die?
- What assets do I own? What is their current worth?
- Do I own the property outright at 100%, jointly owned, or by contract?
- If it is joint ownership, is it considered "tenancy in common" or "with a right of survivorship"?

- Who will care for minor children, aging relatives, pets directly or financially?
- What type of documents do I need, just a will or a trust as well?

Today's presentation focuses on [wills](#) because **everyone should have a will**. It is a legal document. **Holographic** (handwritten) wills are legal in many states, but not in Georgia. Some states use **Statutory Will** forms where you fill in the blanks to complete. This format is not required in Georgia. There are several *online Will creator websites* that you can use to generate a legal will for little or no cost.

[Free Will](#) is an online service that helps to create your own will step by step to comply with state laws. [Good Trust](#) is a fee-based service that generates forms for wills, trusts, POA and directives along with online vault storage for E-documents. A discount code is available for this service through *Triage Cancer*. If your estate is more complicated, contact an estate attorney for legal assistance and in preparing legal documents.

To **make your will legal by law**, certain state requirements must be met.

The will must be in *written format, signed and dated by you, and witnessed by two people unrelated by family ties or personal association*. In many states you must be at least eighteen to prepare a valid will, but in Georgia you only need to be 14 years old with sound mind and decision-making ability.

Some decisions are necessary before creating a will:

1. *Who are the beneficiaries of the will?* Are the assets to be distributed equitably "*in kind*" to all beneficiaries named or are specific assets being listed by item to individual beneficiaries?
2. *What happens if a beneficiary is deceased prior to your death?* Is the estate distributed to the remaining beneficiaries or is there a named successorship to family members of the deceased?
3. *Who is assigned guardianship of minor children?* What age is considered an adult?
4. *Who will be the executor of the will?* Is an alternate executive named in the event the primary executor is unable to fulfill their responsibilities?
5. *Are real properties, personal assets and/or beneficiaries located in multiple states?* This makes estate planning more complex, Consider an *estate trust* to address state specific requirements, financial and tax implications, and avoidance of probate court. A "*pour over*" will is still necessary for any additional assets that were not included in the trust prior to death.

The **will is a legal document that states your wishes and final instructions at the time of death**.

As you start to create the will be sure to include the following items:

- List all *real properties you own* along with their worth.
- List *all personal property and it's (monetary, heirloom, emotional impact) value*.
- Include *intellectual and electronic entities* like online royalties, artwork, and crypto currency.
- Delegate an *Executor to carry out the terms of the will*.
- Triage [Quick Guide to Duties of the Executor](#) explains the typical duties and practical implications to the *executor responsibilities*, role and obligations of the will.
- Determine who will be the *guardian for any minor children*.
- State your final wishes and any arrangements at the time of your death. Do not neglect writing down instructions regarding funeral or memorial arrangements. Your wishes are a welcome relief to family members during this time of sadness.
- Be sure to have all legal documents and supporting paperwork in a secure place so that you and any other persons can easily access them when necessary.

**Power of Attorney (POA), HIPAA, and Advanced Health Directives aka Living Wills** are additional recommended legal documents to have while you are still alive in case of an emergency to oversee your personal affairs, authorize decisions on your behalf, manage daily activities, and carry out end of life instructions.

**Power of attorney (POA)** includes several types of forms: Financial, Healthcare, general and limited power. *A legal and valid POA form grants permission to an authorized designee and must be signed by the person (principal) granting permission and is witnessed and notarized to be legal and binding.*

*Financial Power of Attorney* is authorized to manage your financial matters (banking accounts, retirement investments, household bills and day-to-day activities while you are unable to do so for yourself during your lifetime.

**HIPAA** – *Health Insurance Portability Accountability Act* ensures privacy compliance to your health information and personal health records. Physicians' offices and health institutions are required to acquire HIPAA forms from their patients to access and review medical records, allow designated persons and health professionals specified access, and allow discussion on patient medical concerns with third person designees.

**Advance Healthcare Directive** aka Living Will provides written instructions on your wishes for end-of-life decisions if you are unable to express them yourself. The directive (AHD) looks vastly different in each state, but includes two key sections:

- The first part is selecting *a POA or agent/proxy for managing healthcare decisions on your behalf*. You can choose more than one person as a healthcare agent. This allows someone else to make healthcare decisions when you are unable to make them yourself. Appoint a primary agent and an alternate as POA rather than co-agents to avoid any medical decision conflicts.
- The second part is referred to as *a Living Will*. This section includes decisions in writing on medical care needs and life sustaining measures received continually, for a specified period, or refused for each procedure available. These decisions can include *what life sustaining treatments you do or do not want to receive* (i.e., Hydration, nutrition, resuscitation, and blood infusion to name a few).
- To ensure that specific decisions are carried out by the healthcare agent, POA instructions should be written in the Advanced Healthcare Directive. Be sure that the principal grantor and witnesses have signed the AHD, so it can be executed according to the state law.

Be sure to have conversations with family members to explain the details of your directive as well as your will/trust and support documents. It is just as important to let them know where and how to access your estate plan documents. Remember to include online accounts, logins, and passwords along with your afterlife social media accounts, music, books and online items especially digital photos and videos. And do not forget pets or even that special plant.

People have vastly different opinions regarding traditional funerals or memorials and their wishes on what they want regarding being buried, cremated, organ donations, and military recognition. Also, many do not realize the expenses involved. Funeral insurance and preplanning arrangements may be a viable option in these conversations that are not discussed often enough prior to death. Triage has resources and guidelines on how to go through the process. [\*My wonderful life\*](#) and [\*legacy.com\*](#) are tools that let you share photos, videos, messages, and memories online to family and friends.

*Triage resources can help you through the process.* [\*\*The Estate Planning Toolkit\*\*](#) includes general information about estate planning and what to think about. Section 2 has forms that are specific to your state. The *Georgia Advanced Healthcare Directive* is included in [\*\*Georgia's Estate Planning\*\*](#)

[Toolkit](#) with a sample HIPAA and other forms specific to Georgia along with [specific](#) information about the state rules and how to execute each one of these documents to make sure they are valid. There are lot of other resources to help with estate planning. There are [webinars](#) that go into more in-depth information on estate planning, and a series of [animated videos](#), which are all about five minutes long that are helpful reminders of what to think about when you are starting your estate planning process. You can also [contact our legal and financial navigation program](#) to talk with our team for free about any of the legal issues that you might have questions about. Reminder that checklists, reference guides, and educational videos are available at [TriageCancer.org](#). Note that the **blue text includes reference links** to the Triage website for further information.

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Submitted by Sandy W.

## Meeting Minutes Southside MM Support Group March 22, 2025

### Guest Presentation- Dr. Craig Hofmeister, Emory Winship

Dr. Hofmeister asked questions from the group to focus his presentation on the group's interest. He started his presentation with an overview of myeloma development. Plasma cells consist of monoclonal proteins that form in the bone marrow. It has nothing to do with the protein you eat. The mono (single type) proteins grow rapidly in the bone marrow. If these monoclonal plasma cells circulate in the bloodstream it can lead to kidney failure, hypercalcemia (high calcium in the blood), anemia (low red blood cell counts), and infections from being immunosuppressed (extremely low white cells). The occurrence of these symptoms contributes to the CRAB criteria in diagnosing multiple myeloma.

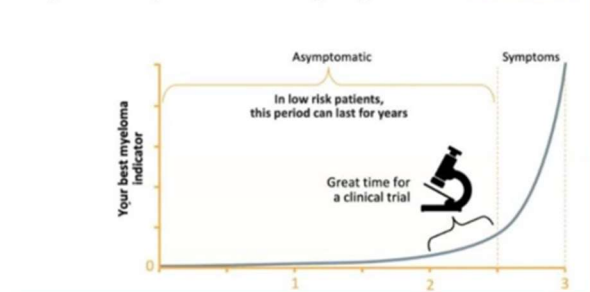
Dr H explained how the term “**risk**” is dependent on its context. Risk in multiple myeloma describes how quickly your disease will become **resistant** to treatment. Your risk level is defined as *low or high* during the staging process of your myeloma diagnosis. High risk [MGUS](#) refers to the likelihood of developing multiple myeloma. If you have *high risk disease* your myeloma is more resistant to treatment. You will need 3 or 4 drug combinations, and the response is generally shorter and less durable. *Low risk* myeloma has fewer symptoms at diagnosis and responds more favorably to treatment. Currently, the average overall survival (OS) is 8-12 years for *low risk* (easier to control) myeloma patients and 2-5 years for patients with more difficulty to treat and control the myeloma.

**Staging** does not mean the same in all cases of cancer. Stage 1 or 2 for tumor cancers indicate that it is isolated to a specific organ with a 50% or better chance for a cure. A tumor cancer that is metastatic has spread to other parts of the body. This is found during the later stage of cancer when curative surgery and treatment is less effective, and survival is shorter. The meaning of *staging* is entirely different in myeloma. Myeloma is a blood cancer that has spread throughout your body making it metastatic at the time of diagnosis. So, staging has nothing to do with location at the time of diagnosis. *Myeloma staging refers to resistance and control to treatment.* *Stage 1* means easier to treat myeloma while *stage 3* is considerably more resistant and harder to control myeloma with treatment. *Stage 2* is

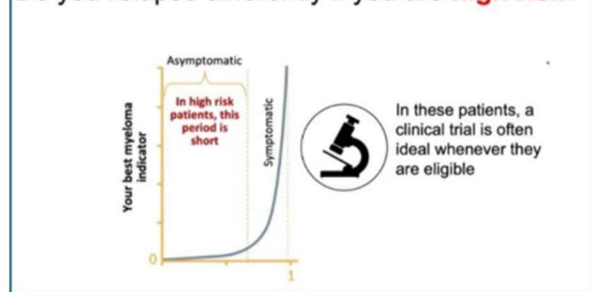
the remaining 60% of myeloma patients that are not easily identified in stage 1 or 3 during initial diagnosis.

*How do doctors determine the **frequency of testing**?*

Do you relapse differently if you are **low risk**?



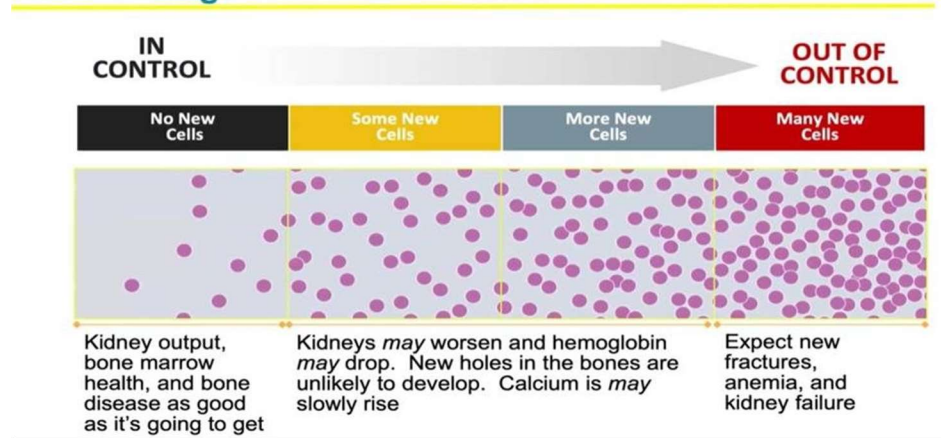
Do you relapse differently if you are **high risk**?



Your disease status is based on your level of risk and response to treatment. In low-risk patients the length of duration of asymptomatic state is much longer and the need for urgency is reduced. High risk disease needs to be monitored much closer and more often to catch the myeloma asap because it is harder to treat and slow down progression. There is very little time to figure out what is causing the number to rapidly go up. The pace of testing changes based on the risk level. Dr. Hofmeister added that if you have low risk myeloma under control and you develop a new symptom, he is going to look for another reason first before suspecting myeloma activity. If you have high risk myeloma with a new symptom he is suspecting the myeloma right away. So, if your myeloma is low risk you can go for longer duration between testing, If the myeloma is high risk, you should evaluate frequently to stay on top of the situation.

Assessing Your Level of Myeloma Disease

How are '**stage**' and '**risk**' different than '**control**'?





**Control** of myeloma refers to the looking at the numbers on your routine blood tests: IG Heavy Chain (IgA, IgG, IgM, IgD), Free Light Chain (kappa & lambda), Protein Electrophoresis (SPEP), and Immunofixation (IFE). You are your best advocate so track your numbers' rising slope over time.

## If you have an IgG-κ or IgG-λ myeloma

Test Names	What is the Test Measuring
<b>IgG</b>	Measures level of Immunoglobulin G.
<b>Serum Protein Electrophoresis (SPEP)</b> Monoclonal immunoglobulin (M-spike, M-protein)	Test measures the monoclonal protein, made by the myeloma cells, and this is <b>subset</b> of the total IgG.
<b>Serum Free Light Chain</b>	Measures involved light chain, kappa or lambda, in the blood

## If you have an IgA-κ or IgA-λ myeloma

Test Names	What is the Test Measuring
<b>IgA (Immunoglobulin A)</b>	Measures level of Immunoglobulin A
<b>Serum Free Light Chain</b>	Measures involved light chain, kappa or lambda, in the blood

In most patients with an IgA myeloma, I don't depend on the SPEP because it is often inaccurate - this is not the case with myeloma.

*What is the difference between refractory and relapse?* **Refractory** means that your myeloma progressed and is uncontrolled while you are on treatment or within 60 days. Patients most commonly become refractory to the current treatment being received. For example, if you are on Revlimid for maintenance and your light chain numbers begin to double and triple, it would be considered refractory to the Revlimid drug. **Relapse** is when your myeloma is uncontrolled no matter if you are on treatment or off treatment. Your myeloma has become active again. The distinction is only relevant on clinical trials for therapies on patient subsets. It is better to watch the numbers. Is the monoclonal protein rising or are the light chains rising or falling? Think of myeloma as *in-control* or *out of control*.

*Can a virus or bad infection cause your myeloma numbers to change?* A severe cold, flu, Covid, RSV can all cause white blood cells to drop or rise as well as your platelets to drop. This typically will not change your myeloma numbers or status. If you become extremely sick, and are hospitalized in the ICU with viral pneumonia, your myeloma may even take a break.

*How often should you get a PET/CT or MRI?* If you have precursor disease MGUS or SMM it is suggested to get evaluated if your M-Spike or light chain numbers have significantly changed in your blood labs. The doctor is looking to see if there is any development in your myeloma bone disease through imaging. If you have myeloma and have been treated, and your numbers are rising, then imaging tests make sense to figure out if bone disease is developing. It is not recommended to get annual or scheduled imaging if your numbers remain unchanged.

Submitted by Sandy W.