



**CLL SOCIETY**

*Smart Patients Get Smart Care™*

# **BEYOND YOUR CLL DIAGNOSIS: COMPREHENSIVE HEALTH MANAGEMENT**

**SEPTEMBER 17, 2024**

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**This Program is Made Possible  
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Support From**

**AstraZeneca** 

 **BeiGene**

**Genentech**  
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# SPEAKERS



**Robyn Brumble**

**MSN. RN  
(WELCOME)**

Director of Scientific Affairs & Research  
CLL Society



**Terry Evans**  
**(MODERATOR)**

24-year CLL Patient and Advocate  
Director, CLL Society Support Network



**Amy L. Goodrich**

**CRNP  
(SPEAKER)**

Nurse Practitioner  
Johns Hopkins Kimmel Cancer Center



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CLL DIAGNOSIS:  
COMPREHENSIVE  
HEALTH  
MANAGEMENT**

# TO DIE WITH IT, NOT FROM IT: CLL SURVIVORSHIP

- With today's treatment advances, the majority of patients with CLL will die of non-CLL causes such as second cancers, vascular disease, infection, stroke, lung disease, renal disease, etc.
- Many of these non-CLL conditions and their risk factors can be identified with routine screening and possibly prevented
- Improvement in treatment has improved survival
- Equally important to improving survival is the need to address overall health



# INFECTIONS

- **People with CLL are at higher risk of infections and severe infections**
- **White blood cells fight infection and even though people with CLL have high white blood cell counts, they do not function normally**
- **Up to 40% of people with CLL have low Immunoglobulin G (IgG) levels up to 3 years before a CLL diagnosis**
- **Others will develop low or lowering IgG levels after their CLL diagnosis from both the CLL and from the treatment of CLL**



# **INFECTIONS DUE TO HYPOGAMMAGLOBULINEMIA** (LOW IGG LEVELS)

- **IgG is an antibody a type of protein produced by the immune system that fights germs and protects us from bacterial and viral infections**
- **IgG antibodies are particular to a specific infection, and therefore remember which germs a person has had in the past, allowing our immune systems to quickly attack them if we are exposed to the same germ again**
- **IgG levels can be monitored with a blood test**
- **Low IgG levels may be associated with higher infection rates, most commonly respiratory tract infections like sinus infections, bronchitis and pneumonia and poor response to vaccinations**
- **People with CLL and a low IgG level and recurrent infections may have IgG replacement therapy recommended, which can be given IV in an infusion center or subcutaneous at home**



# STRATEGIES TO REDUCE INFECTIONS

- **If you are on or have received treatment in the past 6 months and/or receiving IgG replacement therapy, discuss immunizations with your oncology team**
- **You and those close to you should receive all CDC recommended immunizations and boosters**
  - Annual flu vaccine
  - Initial Covid-19 series and all boosters as they are recommended
  - Shingles (all 50 and older PLUS 19 and older with immunocompromise)
  - RSV (all 75 and older PLUS 60-74 at increased risk for severe RSV- that includes CLL)
  - Pneumococcal (age 65 and older)
  - DTaP –diphtheria, tetanus, and acellular pertussis (whooping cough) booster every 10 years



# STRATEGIES TO REDUCE INFECTIONS<sub>(CONT.)</sub>

- **Good handwashing/hand sanitizer**
- **Mask in crowds and avoid crowds when infection rates are high**
- **Know your blood counts and IgG level**
- **Report fevers, shaking chills or any signs or symptoms of infection**
- **Test or be tested for Covid-19, flu, RSV based on symptoms**



# AUTOIMMUNE COMPLICATIONS

- **Impact up to 25% of people with CLL**
- **Autoimmune complications occur when the immune system mistakenly attacks normal cells or tissues**
- **Autoimmune complications are common in people with CLL due to immune dysfunction**
- **In people with CLL, the most common autoimmune complications include Autoimmune hemolytic anemia (AIHA) and Immune thrombocytopenia (ITP)**



# AUTOIMMUNE COMPLICATION TREATMENT

- **Treatment includes:**
  - Prednisone (STEROIDS)
  - Intravenous immunoglobulin
  - Cyclosporin
  - Rituximab
  - For ITP: Thrombopoietin receptor agonist- TPO-Ras- similar to growth factors
  - If autoimmune complications are not well controlled with the above options, CLL directed therapy is recommended, even if CLL is not active



# SECONDARY CANCERS IN PATIENTS WITH CLL

- Cancers unrelated to CLL vs transformation to a more aggressive form of lymphoma
- In people with CLL, up to 63% higher risk of developing a secondary malignancy than age and sex matched general population
- Those at highest risk:
  - Have received chemotherapy
  - Male
  - Between ages of 18 and 69



# SECONDARY CANCERS IN PATIENTS WITH CLL (CONT.)

- **Secondary cancers include:**
  - Skin cancers: Non-melanoma skin cancers most common, melanoma is possible
  - Blood cancers: Acute myeloid leukemia (AML) and myelodysplastic syndrome (MDS). Highest incidence with prior fludarabine
  - Solid tumors: Prostate, colon, breast cancer are most common, many possible



# REDUCING RISK OF SECONDARY CANCERS

- **Regular screening per national guidelines (frequency varies by age and risk factors)**
  - Colon screening- Cologuard/Colonoscopy
  - Prostate screening- Prostate exam and PSA blood test
  - Breast/gyn screening- Mammogram and pap smear
- **Skin Care**
  - Sunscreen
  - Routine dermatology exams
- **Smoking/smokeless tobacco cessation**
  - Many programs available (support groups, nicotine patches, other medications)
  - Regular dental care



# REDUCING RISK OF SECONDARY CANCERS (CONT.)

- **Routine primary care visits with frequency based on health history**
- **Seek out medical care with any persistent or worsening new symptoms**



# CARDIOVASCULAR DISEASE

- Overall rate high of cardiovascular disease in people with CLL due to median age at diagnosis of 72 years
- 1/3 estimated to have significant cardiovascular disease at time of diagnosis and before first CLL treatment
- Some treatments for CLL, mainly BTK inhibitors, increase the risk of cardiovascular disease, particularly high blood pressure/hypertension and abnormal heart rhythms (arrhythmias)
  - You may have a baseline EKG done before starting BTKi
  - Second generation acalabrutinib and zanubrutinib have lower cardiovascular risks
  - If you develop cardiovascular side effects while on BTKi therapy, you may be referred to a cardio-oncologist



# PREVENTING CARDIOVASCULAR COMPLICATIONS

- **Prevention strategies**
  - Regular screening with primary care, regular visits with cardiology, endocrinology, vascular, other specialists
  - Physical activity
  - Healthy diet
  - Weight control
  - Take medications as prescribed
- **Blood pressure control**
  - Home monitoring if applicable
  - Reduce stress/manage anxiety
- **Glucose control**
  - Home monitoring if applicable
  - Follow diabetic diet



# BONE HEALTH

- Higher rates of osteoporosis and fragility fractures in people with CLL when compared to age matched controls
- Fragility fractures are seen without osteoporosis
- Enzymes and other substances secreted by CLL cells cause increased bone loss and reduced bone replacement/repair
- Treatment of CLL may reduce bone loss
  - Steroids promote bone loss



# PROMOTING/MAINTAINING BONE HEALTH

- Optimize vitamin D and calcium levels with primary care input
- Engage in weight bearing exercise
- Bone density screening if high steroid exposure or other risk factors
- Prompt and early referral to bone density/metabolic bone clinic
- Early antiresorptive therapy as appropriate
- Physical/occupational therapy or exercise physiology referrals as appropriate



# DENTAL HEALTH

- **Limited research**
- **Increased rates of dental disease and higher rates of dental treatment needs**
- **Highest incidence in use of chemotherapy for the treatment of CLL**
  - Mouth dryness common with chemotherapy (decreased saliva)
- **Strategies to reduce risk**
  - Regular dental care
  - Optimizing dental/oral hygiene



# EMOTIONAL AND PSYCHOLOGICAL HEALTH

- Psychological impact of CLL diagnosis is understudied
- Chronic, slow growing, minimal symptoms and observation/watch and wait results in uncertainty and is commonly not what patients anticipate after getting a cancer diagnosis
- Emotional quality of life surveys show reduced results in patients with CLL and results do not improve over time
- Anxiety often reported around the time of medical visits
- Financial strain
- No difference in depression, anxiety and overall quality of life in patients under active surveillance/observation vs those in active treatment



# STRATEGIES TO IMPROVE/MAINTAIN EMOTIONAL AND PSYCHOLOGICAL HEALTH

- Screening at diagnosis, at regular intervals and with change of disease status/treatment initiation
- Early referrals to psychology/counseling
- Close involvement with primary care provider
- Caregiver support
- Social work referral
- Local cancer support services
- Support Groups
- Individual peer support



# CLL SOCIETY'S PATIENT AND CARE PARTNER SUPPORT GROUPS



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**PATIENT &  
CARE PARTNER  
SUPPORT  
GROUPS**

- **Approximately 40 support groups held virtually in the US and Canada.**
- **CLL Society has supports groups specific to Watch & Wait and Veterans with CLL.**
- **Support groups are a place of camaraderie and knowledge sharing among members.**



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# CLL SOCIETY 1-ON-1 SUPPORT PROGRAMS

## Emotional & Spiritual Advocate Program

- 1-on-1 support from a board-certified chaplain for people of all faiths or no faith background.
- Help with exploring coping mechanisms, spiritual/theological reflection, meaning making, goals of care conversations, grief/bereavement support, and more.



<https://cllsociety.org/emotional-advocate>

## Peer Support Program

- 1-on-1 support from an individual impacted by CLL.
- A Peer Support Volunteer can share their own experiences to help you navigate the watch and wait period, insurance, newly diagnosed questions, making treatment decisions, managing side effects, and more.



<https://cllsociety.org/programs-and-support/the-cll-society-peer-support-program/>



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# AUDIENCE Q&A



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# THANK YOU FOR ATTENDING!

Please take a moment to complete our post-event survey,  
your feedback is important to us

If your question was not answered,  
please feel free to email: [asktheexpert@cllsociety.org](mailto:asktheexpert@cllsociety.org)

Join us for our next webinar,  
**GETTING THE MOST FROM YOUR CLL TREATMENT: MANAGING SIDE EFFECTS  
AND KNOWING WHEN TO STOP**  
on October 16<sup>th</sup>

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the long life of the CLL SOCIETY by supporting our work:  
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